

GUARDIANSHIP OF ADULTS
A
DECISION-MAKING GUIDE
FOR
FAMILY MEMBERS, FRIENDS AND ADVOCATES

ROY FROEMMING, J.D.
WISCONSIN COALITION FOR ADVOCACY

BETSY ABRAMSON, J.D.
ELDER LAW CENTER
COALITION OF WISCONSIN AGING GROUPS

WISCONSIN DEPARTMENT OF HEALTH AND FAMILY SERVICES
DIVISION OF SUPPORTIVE LIVING

FALL, 1997
REPRINTED WINTER, 2000

This handbook is a revision of an original version written in 1984 by Roy Froemming and Ken Streit. Preparation of the 1997 revision was funded by the Bureau of Aging and Long Term Care Resources, Division of Supportive Living,

Department of Health and Family Services. The opinions in this book are those of the authors, and do not necessarily represent the opinions of any government or private agency.

For additional copies, contact:

Department of Health and Family Services
Division of Supportive Living
ATTN: Publications Order
One West Wilson St.
P.O. Box 7851
Madison, WI 53707-7851

Requests should be made by either completing a DMS-25 FORMS/PUBLICATIONS ORDER or by sending a written request which includes the publication identification number (PSL-460), the number of copies, your name, a complete return address (including street address) and a phone number where you can be reached in case questions arise.

**The Wisconsin Department of Health and Family Services
Bureau of Aging and Long Term Care Resources**

The Bureau of Aging and Long Term Care Resources (BALTCR) has the responsibility for analyzing public policy options and for planning and managing the delivery of services for persons who are elderly, persons with physical disabilities, persons in need of elder abuse and/or adult protective services and persons who need or receive community based long-term support. The Bureau carries out its responsibilities in a way which actively promotes individual choice, dignity, reputation, relationships, overall health, community participation, and self sufficiency.

The Bureau includes the following: an Office for Persons with Physical Disabilities, an Aging Network Operations Section, a Long Term Support Administration Section and the WisTech project (federally funded project which provides information and referral regarding assistive technology for provider agencies needing adaptive equipment). For more information on the Bureau telephone (608) 266-2536 or write: Bureau of Aging and Long Term Care Resources, One West Wilson St., P.O. Box 7851, Madison, WI 53707-7851.

PREFACE

Questions about guardianship are raised by people with disabilities, spouses, relatives, friends, advocates and providers of residential, vocational, medical and other services. This handbook provides an overview of guardianship and also tries to respond to questions that are often asked about the nature, purpose and effects of guardianship, alternatives to

guardianship, and ways to tailor guardianships to individual needs. In some cases the handbook provides specific answers. For example, it describes circumstances under which a guardian has authority to place a person in a residential setting without a separate court order. In other cases, such as the role of a guardian in advocating for a disabled person or the right of a person declared incompetent to associate with others, the handbook tries to provide a framework for thinking through the questions in a way that makes sense for the individuals and the situations in which they are living.

The law in Wisconsin often does not clearly define the powers and duties of a guardian in specific situations. This handbook tries to provide some guidelines where the law is unclear. The handbook also provides suggestions on how to be an effective protector and advocate for the person, as well as how to meet legal requirements. The reader should understand that these guidelines and suggestions are the opinions of the authors, and that other people may have other interpretations.

This handbook tries to avoid technical language and generally does not include citations to statutes and cases. Readers interested in more detail or in looking up the legal source material should refer to chapters IV-VI of *Chapter 55: Protective Services Law and Its Application*. (See Section X for ordering information.)

TABLE OF CONTENTS

	<u>Page</u>
I. WHEN IS A GUARDIAN NEEDED?	1
A. What Is a Guardian?	1
B. What are the Different Kinds of Guardians?	1
C. Advantages and Disadvantages of Guardianship	2
D. Finding of “Incompetence”	3
E. How Should Competence be Evaluated?	3
F. Other Factors that Affect Need for Guardianship	4
II. ALTERNATIVES TO GUARDIANSHIP	5
A. Introduction	5
B. Financial Management Advance Planning Alternatives	5
1. Joint Bank Accounts	5
a. Joint Tenancy Accounts	5
b. Dual Signature Checking Accounts	6
2. Power of Attorney	6
3. Conservatorship	6
4. Representative Payment	7
5. Trusts	7
C. Health Care Advance Planning Alternatives	8
1. Living Wills	8
2. Powers of Attorney for Health Care	9
3. Do-Not-Resuscitate Orders	10
III. TAILORING GUARDIANSHIPS TO INDIVIDUAL NEEDS	11
A. Seeking the Least Possible Restriction on Personal Liberty	11
B. Use of Limited Guardianship	11
C. Involvement of the Individual in Decision-Making After Guardianship is Created	13
IV. PROCEDURE FOR APPOINTMENT OF A GUARDIAN	13
A. Petition and Hearing	13
B. Choice of Guardian	14
C. Temporary Guardianship	14
D. Costs of Guardianship	15
E. How Does a Guardianship End?	15
V. POWERS AND DUTIES OF A GUARDIAN OF THE PERSON	16
A. Role of a Guardian of the Person	16
B. What is the Balance Between the Guardian’s Power to Protect and the Person’s Constitutional Rights? ..	17
C. What Factors Determine What is “Least Restrictive”?	18
D. Securing Appropriate Care and Services	19
E. Choosing Medical and Psychological Treatment	20
1. Introduction	20

2. What is an Informed Consent?	20
3. Customary Medical Treatment Decisions	20
4. Procedures that Only Benefit Others	21
5. Treatment for Mental Disabilities; Behavior Modification; “Drastic” Procedures	22
6. Decisions to Withhold Life-Prolonging Treatment	23
7. Sterilization, Birth Control and Abortion	24
F. Making Residential Placements for Care, Treatment or Supervision	25
G. Admitting the Person for Psychiatric Hospital Care	25
H. Court-Ordered Services and Placement	26
1. The Protective Service System	26
2. Protective Placement	27
3. Protective Placement Reviews	29
4. How Do Funding Issues Affect Protective Placement?	30
5. Commitment	31
I. Checklist for Guardians of the Person	31
1. Annually	31
2. Monthly	32
VI. GUARDIANSHIP OF THE ESTATE	32
A. What is the Responsibility of a Guardian of the Estate?	32
B. Legal Requirements of a Guardian of the Estate	36
1. What a Guardian of the Estate Must Do	36
2. What a Guardian of the Estate May Do Without Approval of the Court	36
3. What a Guardian of the Estate May Do Only With Specific Prior Approval of the Court	37
4. What a Guardian of the Estate May Not Do	38
VII. PRESERVING AND PROTECTING THE PERSON’S RIGHTS	38
A. Introduction	38
B. Constitutional Rights	39
1. Balancing Constitutional Rights with the Guardian’s Responsibility to Protect the Person’s Best Interests	39
2. The Right to Life	40
3. The Right to Freedom of Movement and Choice of Residence	40
4. The Right to Freedom of Speech and Religion	41
5. The Right to Associate with people of the Person’s Own Choosing	41
6. The Right to Privacy; Reproductive and Sexual Rights	42
7. The Right to Due Process of Law	43
8. The Right to Have Access to Government and the Courts	43
9. Right to Vote	43
C. Other Civil Rights	43
1. Right to Marry	44
2. The Right to Obtain Driver’s Licenses and Other Licenses	44
3. The Right to Testify in Any Judicial or Administrative Proceeding	44

D. Property Rights	44
1. The Right to Hold or Convey Property	44
2. The Right to Contract	45
E. General Human Rights – Respect and Dignity	46
F. Rights in Nursing Homes and Residential Facilities	46
G. Bill of Rights for People Receiving Institutional or Community Services for Mental Illness, Developmental Disabilities, Alcoholism or Drug Abuse	48
1. Treatment Rights	48
2. Personal Rights	49
3. Grievances and Legal Remedies	49
4. Other Rights	50
 VIII. COMMUNITY SERVICES FOR PEOPLE WITH MENTAL ILLNESS, DEVELOPMENTAL DISABILITIES OR ALCOHOL OR DRUG ABUSE PROBLEMS	50
A. What are Community Services?	50
B. Learning How Your Local Community Service System is Organized	51
C. Community Services for People with Mental Illness, Developmental Disabilities or Alcohol or other Drug Use	52
D. Social Service Departments	53
E. County/Tribal Aging Units	53
F. Elder Abuse Agency	53
G. Protective Services Agency	54
H. Community Options Program and Community Integration Program	55
I. Community Support Services for People with Mental Illness	57
J. Home Health and Personal Care Services	57
K. Supplemental Security Income Exceptional Expense Supplement	57
 IX. LEGAL ASSISTANCE	57
 X. LEARNING MORE	58

APPENDIX: RESOURCE LISTS

Legal Advocacy Resources

Statewide Disability and Aging Organizations

State Government Disability and Aging Offices

Independent Living Centers and Wisconsin Alzheimer's Association Chapters

I. WHEN IS A GUARDIAN NEEDED?

A. *What is a Guardian?*

A person with a severe mental disability may be unable to exercise some or all of his or her own rights or to protect his or her own interests. A *guardian* is a person appointed by a court to take the place of the person in exercising the rights he or she is unable to exercise, to make (or help make) decisions the person is unable to make independently, and to be an advocate for the person's interests.

A guardianship is created by a court order, and the guardian only has the powers that state law and the court order provide. Any person in Wisconsin over the age of 18 is legally an adult, and is presumed to be able to manage his or her own financial affairs, choose where to live, consent to medical treatment, vote, make contracts, marry, and exercise his or her own legal rights as an adult. This presumption does not change because a person has a disability.

The presumption that an adult is competent to make his or her own decisions often comes as a surprise to family members, who may find themselves with no legal right to be involved in, or even know about, care that a relative is receiving. For example, family members may be refused information about the person's needs and treatment because he or she is unable, or refuses, to give informed consent to release of the information.

B. *What are the Different Kinds of Guardians?*

There are two basic kinds of guardians, a guardian of the estate and a guardian of the person. A court appoints a *guardian of the estate* for a person who is incompetent to handle his or her own finances. A court appoints a *guardian of the person* for a person who is incompetent to provide or arrange for personal needs, such as the need for shelter, food, medical care, or social services. A court may appoint the same person as guardian of both the estate and the person, or the responsibilities may be divided.

For both personal and financial guardianships, a court may establish either a *full* or a *limited guardianship*. Under Wisconsin law, the court can (and should) make specific findings as to the rights and powers a person is not competent to exercise, and should limit guardianship to those rights and powers. For example, if a person is competent to handle his or her salary or a small personal allowance but not a large bank account, the court may limit the financial guardianship to allow the person to continue to manage his paycheck or allowance. Similarly, the court can limit a guardianship of the person to recognize the person's ability to vote, marry, drive, contract, choose a place to live, etc. To protect the person's rights, self-image, and opportunity to learn, the powers of a guardian should be carefully limited to areas where the person clearly needs a substitute decision-maker. (See Section III.)

A *standby guardian* is a person appointed by the court to become guardian upon the death, incapacity or resignation of guardian. The standby guardian must inform the court when he or she begins to exercise the powers of a guardian.

A *temporary guardian* is appointed only for a limited period of time, and his or her powers must be limited in the order to authority over specific property or specific acts.

C. Advantages and Disadvantages of Guardianship

If a person is genuinely unable to protect himself or herself, or to understand his or her rights, a guardianship can be an important tool for protecting the person from abuse, neglect or exploitation, and for ensuring that there is someone able to understand and assert the person's rights. For example:

- A person may need money for food and shelter, medical care, or rehabilitation services but may be unable to identify or apply for assistance. A guardian can monitor the person's need for assistance, make the application, and appeal if benefits are denied.
- A person who does not understand the value of money may give away his or her monthly check to someone who is exploiting the person's lack of understanding. A guardian can limit access to funds and control how they are spent.
- A person in an institution may be physically restrained much of the day, without being able to challenge what is happening, because this is easier for staff. A guardian can protect the person's right to freedom from unnecessary restraint, to appropriate treatment, and to the least restrictive residential placement.

Thus, a guardianship can protect as well as restrict rights. However, some rights (like the right to vote, to marry, or to consent to sterilization) are considered so personal that a guardian cannot exercise them and they are lost completely unless the court finds that the person is competent to exercise them on his or her own.

On the other hand, a guardianship that is not justified by the person's real needs, or that is more restrictive than necessary, has substantial costs:

- The process of establishing that a person is incompetent is often a painful one, not only for the person but also for friends and family members who are called upon to squarely face and discuss the question of what the person can and cannot do.
- A person found incompetent loses many basic, day-to-day rights, and may also feel a loss of dignity and respect because he or she must seek the consent and assistance of another person for many activities that other people take for granted. Other people may see the person as less capable than he or she actually is.
- Loss of rights may reduce the persons' opportunity to learn to make choices, and thus to develop or keep decision-making skills.

For these reasons, a guardianship should be sought only if it is clearly for the benefit of the person, and not because it is easier or more convenient for others to make decisions for him or her. If a guardianship is sought, it should be tailored to deprive the person of control over a part of his or her own life only when there is a functional reason.

D. Finding of "Incompetence"

The ability of a person to manage his or her own affairs is called "*competence*." Before a judge can appoint a guardian for a person, the judge must find that the person is "*incompetent*." Legal incompetence is a finding by a court that:

- The person has a mental disability, such as mental retardation, brain injury, chronic mental illness or organic brain damage caused by advanced age. The disability must be long-term and must substantially impair the person from providing for their own needs. Physical disability by itself is not enough to establish incompetence.
- Because of the mental disability, the person is substantially incapable of managing his or her property (for financial guardianship) or of caring for himself or herself (for personal guardianship), or both.

A person is not incompetent simply because he or she knowingly and voluntarily chooses to do something most of us would consider foolish. All of us have a right to make mistakes. The guardianship law can only be used to protect those who are unable to provide for their own needs, not those who are able but unwilling to do so.

A person also cannot be considered incompetent because of failure to understand something that was not explained in the way that he or she was most likely to understand, or because it may take extra time and effort on the part of other people to communicate with the person. These problems should be dealt with in other ways, such as use of interpreters and development and use of alternative communication methods.

It is most useful to think of competence in terms of the person's ability to understand the nature and consequences of a particular action or decision, if information about the action or decision is presented in a form the person is most likely to understand, and then to make decisions that take that information into account. For example, with regard to consent to medical treatment, the test might be whether, after the treatment is explained to the person in the clearest possible way, the person can understand the benefits and risks of the treatment and of any alternative types of treatment, and can make a rational decision based on available facts.

Incompetence is not an all-or-nothing concept. Some people can understand most of the decisions they face in everyday life, but may need help with financial management or complex medical decisions.

E. How Should Competence be Evaluated?

The most useful way to determine whether a person needs a guardian, and for what purposes, is to break down the person's need for support and protection into functional areas, such as medical decisions, personal needs, safety, relationships, etc. For each of these functional areas, the evaluator can then ask the questions:

- What decisions does the person face in this issue area? What decisions is s/he likely to face in the future?
- For decisions relevant to his/her life, is the person substantially able to understand all significant information on the nature, risks and benefits of the various options, if explained to him/her in a form s/he is most likely to understand? If not, is this inability due to a substantial, long-term mental disability?
- Has the person had the opportunity to develop decision-making capacity through training and practice? Has the person had needed evaluation, training, and therapy to develop receptive and expressive language skills or provide alternative communication methods? If not, would this be likely to develop or restore decision-making ability?

- Where the person lacks the evaluative capacity to make a knowing choice, does this incapacity have a substantial impact on his/her ability to manage finances or care for him/herself?

In this approach, knowledge of the person's day to day skills and of the practical issues he or she is likely to face are at least as important as diagnostic skills. Ideally, information from formal medical or psychological testing should be combined with information gathered from people who know and work with the person in his or her typical environments.

F. Other Factors that Affect Need for Guardianship

Need for a guardian will depend not only on a person's abilities but also on his or her personal situation. Some people who could clearly qualify for guardianship are functioning well without one. Others who have greater skills may be in need of protection because they are highly vulnerable. Factors include:

- **Availability of informal social supports.** If the person has family, friends or a volunteer citizen advocate willing to play an active role in helping him or her make decisions, he or she may be able to function well without a guardian, so long as he or she is able to know when help is needed and how to seek it. A person who is willing to have his funds deposited into a two-signature checking account usually will not need a financial guardian. A person who brings major decisions to a support circle of family, friends and paid support workers may not need any guardian, or may only need one for complex medical decisions.
- **Availability of formal support services and treatment.** A strong network of support services that both protects the person from unacceptable risks and actively works to help the person develop and practice skills in decision-making, health and nutrition, self-protection, personal care, care of the home, etc, can be as protective as a guardianship and more effective in teaching long-term independence.
- **Dependence on services/institutional placement.** Heavy dependence on medical, social or mental health services may itself create a need for guardianship. These agencies can be very powerful, and a guardian may be the only means to provide outside monitoring of how that power is used. This becomes particularly true in services, such as institutions, that are isolated from the larger society and/or have the potential to control every aspect of a person's life.

Much depends on the attitude of the person and those around him or her. For voluntary support systems to work, the person must be willing to accept help. Those relied on for help must be supportive of the person's rights. It is essential to be alert for conflicts of interest: family members may be motivated by a desire to hold on to the person's funds; service providers may act out of desire to minimize their own workloads or expenses. Unless there are checks and balances over the power of others, a guardian may be a necessary protection.

II. ALTERNATIVES TO GUARDIANSHIP

A. Introduction

Because guardianship labels the person "incompetent" and takes away legal rights, it is something that should only be

used when it is clearly needed. One alternative to guardianship, providing a good support system and helping people to make decisions for themselves, is mentioned above in Section I-F.

The other alternatives to guardianship discussed below generally provide fewer outside checks on the substitute decision-maker. They are often effective as ways to make sure that basic needs for food, clothing, shelter and medical care are met, without establishing a guardianship. If set up and used correctly, they may more closely carry out the person's wishes than a court-ordered guardianship. However, they may also provide less protection for the person, such as a hearing before they are established and continuing oversight by a court.

B. Financial Management Advance Planning Alternatives

IMPORTANT NOTE: *With the exception of 4., Representative Payment, all of the options listed below must be set up while the individual is still competent.*

1. Joint Bank Accounts

a. Joint Tenancy Accounts

This option involves setting up a bank account that permits one individual "or" another to access a bank account. It is similar to accounts held by married couples where "Mrs. Jones OR Mr. Jones" can write checks, withdraw from savings accounts, etc. It can be especially useful when individuals have physical disabilities which prevent them from shopping, cashing checks or paying bills. It is important to note that funds held in joint tenancy can be misused, so this option should be exercised with caution and only when the person with whom the agreement is made is fully trusted. This may not be the best choice if the individual is mismanaging his or her funds, since the individual will still have total access to the account. Also, at the time of the death of one of the parties, the funds become the sole property of the other individual named on the account.

b. Dual Signature Checking Accounts

A dual signature checking account allows the person to make out his or her own checks, but requires the person to get another person's signature before the checks can be used. This can be a very useful way of letting the person retain responsibility and learn financial management while preventing major errors in judgement. These accounts require that both persons sign a check before it will be paid and thus the accounts read "Mrs. Elder AND Donna Daughter," signifying that before a check will be cashed or a withdrawal honored, BOTH parties must sign. Like the joint tenancy bank account, the dual-signature account may be set up at a bank. It is fairly simple to do so.

CAUTION: Funds in these bank accounts appear to belong to both individuals so there is a danger that the more competent signer could exercise undue influence. Also, at the time of death, the money in the account becomes frozen.

2. Power of Attorney

If the person is competent to understand his or her action, he or she can give another person, called an "attorney-in-fact," the power to manage all or part of his or her finances. A power of attorney should be in writing and can be limited only to certain property and powers. For example, an attorney-in-fact could be given power to manage and rent out the person's real estate, but not to sell it. An ordinary power of attorney can be withdrawn at any time, and ends automatically if the person dies or becomes incompetent.

Under Wisconsin law, it is possible, and indeed generally advisable, to establish a "*durable* power of attorney" which continues even if the person who establishes it later becomes incompetent, or first becomes effective when the individual becomes mentally incapacitated. This gives a person a way of planning ahead by specifying who the person wants to act in his or her place if he or she becomes incompetent. Unlike a guardianship, however, there is no supervising court to oversee the use of funds and to replace the financial manager if circumstances change and therefore this is an area that is ripe for abuse. This is one reason that a private attorney should be used in setting up the powers of attorney to ensure that legal requirements are met and that the client is adequately protected. This could include putting in restrictions on making gifts of the principal's property and requiring regular accounts to third persons.

3. Conservatorship

If the person is competent to understand his or her action, he or she can request the court to appoint a conservator who has exactly the same powers and responsibilities as a guardian of the estate. Conservatorship is different from guardianship in that there is no finding of incompetence and the person can ask the court to end the conservatorship at any time. The conservatorship may then be continued only if the court holds a hearing, finds that the person is incompetent to handle his or her finances, and appoints a guardian of the estate to handle financial and property matters. A conservatorship's advantage over a durable power of attorney is the built-in required court accounts and court oversight. It does, however, involve attorney's fees and a court appearance to set it up.

4. Representative Payment

If it is determined that a person is incapable of managing his or her Social Security, Supplemental Security Income

(SSI), Railroad Retirement of Veterans Administration benefits, the appropriate government agency has the authority to appoint a "representative payee" to receive the checks and use them for the benefit of the person. This is often done on the basis of an application from a relative or caretaker and a statement by a physician or psychologist about the person's financial competence. No court action is needed, and a hearing is held only if the person requests it. The payee must hold the funds in a separate account, make sure that benefits are used first for the support and maintenance of the person, and must meet the agency's reporting requirements. Persons with mental or physical disabilities or chemical abuse problems which prevent them from managing their money properly may benefit from this device which results in the government issuing the check to "John Jones for the Benefit of Edward Elder."

Unlike all of the other alternatives suggested in this section, representative payment is available even after the onset of incapacity. It may be adequate for clients of moderate means whose primary, if not sole, source of income are one of these types of government benefits.

The application for representative payment is usually made by the person responsible for care of the beneficiary. The government must contact the beneficiary's physician and initiate contact with the doctor, asking whether the doctor believes the individual is capable of managing his or her money. The person can appeal both the need for representative payment and the choice of payee.

Representative payment has the advantage that the person's control over other aspects of his or her life are not directly affected. On the other hand, control over a person's only source of income can give a representative payee powers almost as great as a guardian's, without many of the procedural protections. If a person is in need of extensive advocacy and protection in seeing to personal needs, representative payment should not be used as a substitute for guardianship. This system thus presents some risks and should be used cautiously; there are minimal accounting requirements and few safeguards, although the government agency may require an accounting from the representative payee and can investigate allegations of misuse of funds.

5. Trusts

Under a trust, resources are transferred by a "grantor" to a trust, with a "trustee" appointed, to use the funds for the benefit of the "beneficiary." If the transfer is made during the grantor's lifetime, with the grantor permitted to change any terms of the trust, it is called a "living trust." If the transfer is made without the grantor being able to change any terms of the trust, it is called an "irrevocable living trust." The "trustee" may only use the resources in the way and for the purposes set out by the person creating the trust. For example, a parent of a disabled person could transfer resources to a trust, directing the trustee to use those resources for the benefit of his son or daughter (the "beneficiary" of the trust). The trust provides a way of making resources available for the benefit of the person while leaving management and decisions in the hands of the trustee.

Or, an elder person starting to experience some dementia may transfer some of her funds to a trust, naming herself as the current trustee, but naming another individual as the "successor trustee" to take over when her dementia progresses to the point where she can't manage her own finances anymore. The elder herself would likely also be the beneficiary in this case.

In some cases, resources cannot be given directly to another person, even through a trust, because the individual would lose Medical Assistance or Supplemental Security Income benefits. Funds in a trust are generally not counted as resources for these programs as long as the person does not have a direct or automatic right to use of the funds for his or her basic support. Generally, these trusts are written to leave use of the funds up to the trustee, who is directed in the trust document to supplement rather than replace public benefits (e.g., by paying for medical, social or other services not available under public programs.) For more information on trusts, see *One Step Ahead: Resource Planning for People with Disabilities Who Rely on Supplemental Security Income and Medical Assistance*, available from the Wisconsin Council on Developmental Disabilities.

In the type of trust described above, the beneficiary must rely on the trustee to put the resources of the trust to use. The trustee will need to be someone who will actively work to identify and meet the special needs of the person, and who will involve the person in decision-making to the greatest extent possible. If the trustee does not know the person well, a relative or advocate may be able to take the role of identifying needs to the trustee.

Trusts are extremely complicated and the advice of an attorney should be sought to create the trust. The attorney should be familiar both with the needs of people with disabilities and with the requirements of any public benefits the person may be eligible for. Do-it-yourself mail order kits should not be used as they do not take into account Wisconsin laws regarding property transfer, marital property or taxes.

C. Health Care Advance Planning Alternatives

1. Living Wills

Also known as the "Declaration to Physicians," a Living Will is a short state form that an individual can fill out indicating that he or she does or does not want life-sustaining treatment and/or feeding tubes used if the signer is ever in: (1) a "persistent vegetative state" or (2) a "terminal condition with death imminent." It does not appoint an agent or anyone else to make the decisions for the person. Rather, it is a statement from the signer to physicians telling the physicians that the signer does or does not want these treatments if ever diagnosed by two physicians to have one of these conditions.

While the Living Will is an excellent and simple tool for these situations, as explained below, it is less comprehensive than the Power of Attorney for Health Care. Individuals may complete both documents, taking care that they do not conflict with each other. To receive a copy of the Living Will, send a self-addressed envelope to: Wisconsin Department of Health and Family Services, Division of Health, P.O. Box 309, Madison, WI 53701-0309.

REMINDER: Individuals must be competent to complete a Living Will. A guardian may not complete a Living Will for his or her ward.

2. Powers of Attorney for Health Care

Competent individuals may complete a state form indicating who they would want to make medical decisions for them if they ever become mentally incapacitated. The signer, called the "principal," appoints a "health care agent," or simply "agent," to make these decisions after they have been personally examined by two physicians (or one physician and one

psychologist) certifying that the individual is "incapacitated" meaning that he or she is no longer capable of making medical decisions for themselves. Specific authority must be given to the agent to make decisions regarding admitting the principal to a nursing home or community-based residential facility, withholding or withdrawing feeding tubes, or continuing to make decisions if the principal later becomes pregnant. An alternate agent may also be selected. The agents selected may be friends or family members. A health care agent may not be a health care provider for the person, or the spouse or employee of a health care provider, unless he or she is also a relative of the person. There are specific requirements regarding witnessing.

In making decisions under a Power of Attorney for Health Care, an agent must make decisions consistent with what the principal has previously told him or her, as specifically written in the document or what the agent believes the principal would want. In other words, the agent is to make decisions the *principal* would want ("substituted judgment") not what the agent thinks would be in the principal's "best interests." It is helpful for the person creating the power of attorney to think through what he or she would want in different situations, and to give the agent as much direction as possible, either in the power of attorney document or through separate documents.

The Power of Attorney for Health Care is the most comprehensive health care advance planning alternative. Unlike the Living Will, which is limited to situations where the individual is in a persistent vegetative state or in a terminal condition, the Power of Attorney for Health Care can be followed any time the principal is incapacitated (for example, dementia, Alzheimer's, after a stroke, after a brain injury, etc.). Additionally, the Power of Attorney for Health Care applies to more kinds of treatment than the Living Will. The Living Will only gives direction about life-sustaining treatment and feeding tubes; the Power of Attorney for Health Care can give the agent authority regarding virtually any treatment except for mental health admissions, experimental mental health treatments and other more controversial and extreme procedures. For example, the Power of Attorney for Health Care, but not the Living Will, would address situations requiring a decision about agreeing to home care, starting physical therapy, setting a broken leg, taking certain medications, etc.

To receive a copy of the Power of Attorney for Health Care, send a self-addressed envelope to: Wisconsin DHFS, Division of Health, P.O. Box 309, Madison, WI 53701-0309.

REMINDER: Individuals must be competent to complete a Power of Attorney for Health Care. A guardian may not complete a Power of Attorney for Health Care for his or her ward.

3. Do-Not-Resuscitate Orders

A "Do-Not-Resuscitate (DNR) Order" is a written order directing emergency medical technicians, first responders and emergency health care facilities personnel not to attempt cardiopulmonary resuscitation on a person for whom the order is issued if that person suffers cardiac or respiratory arrest. It is important to note that because of the statutory definitions, these documents are **only** directed at emergency medical technicians, first responders and emergency health care facilities personnel.

Other types of DNR Orders (e.g., those that apply in in-patient hospital settings) are not covered under this law. The execution of a DNR Order is different from execution requirements for Living Wills and Powers of Attorney for Health Care, specifically in that while Living Wills and Powers of Attorney for Health Care are executed by competent individuals and are subject to witnessing requirements, DNR Orders may only be issued by physicians and are not subject to witnessing requirements.

A Living Will or Power of Attorney for Health Care is executed by an adult, at least age 18, of "sound mind." A DNR Order, however, may only be issued by a physician and then only when the person is a "qualified patient." Under the statutes, a "qualified patient" is an individual who:

- Is age 18 or over;
- Has a medical condition such that, were the person to suffer cardiac or pulmonary failure, resuscitation would be unsuccessful in restoring cardiac or respiratory function or the person would experience repeated cardiac or pulmonary failure within a short period before death occurs; and
- Has a medical condition such that, were the person to suffer cardiac or pulmonary failure, resuscitation of that person would cause significant physical pain or harm that would outweigh the possibility that resuscitation would successfully restore cardiac or respiratory function for an indefinite period of time.

Once the order is issued, the attending physician (or a person directed by the doctor) must provide the patient with written information about the resuscitation procedures that the patient has chosen to forego **and** the methods for the patient to revoke the document.

After providing this information, the attending physician or the person directed by the attending physician is required to affix a **Do-Not-Resuscitate Bracelet** to the patient's wrist and document in the patient's medical record the specific medical condition that qualifies the patient for the order. The Department of Health and Family Services is required to develop rules about the bracelets.

The DNR Order would come into play when a person for whom the order is issued suffers cardiac or respiratory arrest. Then emergency medical technicians (EMTs), first responders and emergency health care facility personnel are required to follow the order. The only exceptions are when the medical personnel know the individual revoked the document, the bracelet appears tampered with or removed or if they know the individual is pregnant.

To receive more information about Do Not Resuscitate orders, write to: Wisconsin DHFS, Division of Health, P.O. Box 309, Madison, WI 53701-0309.

NOTE: A competent individual may request a DNR Order from his or her physician, or a guardian or agent may request a DNR order on behalf of the ward or principal.

III. TAILORING GUARDIANSHIPS TO INDIVIDUAL NEEDS

A. Seeking the Least Possible Restriction on Personal Liberty

Generally under Wisconsin law, protective supports, including guardianship, should be the least restrictive necessary to achieve their protective purpose. This means:

- Identifying **alternatives to guardianship** and determining if they would be less restrictive. Alternatives may or may not be less restrictive; lack of court oversight may give greater rather than less control to an alternative decision-maker.
- Using **limited guardianship** to ensure that the person does not lose rights which he or she is capable of exercising.

The result of an unnecessarily restrictive guardianship is not only loss of rights for the person, but unnecessary dependence, waste of the guardian's time, and unnecessary conflict between the guardian and the person over issues where the guardian does not really need to be involved.

B. Use of Limited Guardianship

Wisconsin law requires a court to make specific findings as to which legal rights an individual is competent to exercise. In a finding of limited incompetence, a guardianship of the person must be limited in accordance with the court order. The statute lists several rights which the individual can be found competent to exercise. The listed rights are: the right to vote, to marry, to get a driver's license or other state license, to hold or convey property and to contract. This list is not exclusive: the law specifically provides that other rights can also be retained. Findings of incompetence must be based on clear and convincing evidence. If there is no evidence relating to an area of decision-making, the presumption should be that the person is competent in that area.

Rights that may be retained and should be at least considered in each evaluation include:

- **Right to vote.** A guardian has no power to vote for the person. The standard for competence to vote is that the person must be **capable of understanding the purpose of the electoral process.**
- **Right to marry.** A person must be legally and actually competent to marry. A guardian has no power to consent to marry on behalf of the person. If a guardian of the person is appointed, the right to marry must be reserved to the person or it is completely lost. The test should be whether the person understands the nature and consequences of marriage.

- **Contract and hold and convey property.** If no guardianship of the estate is being established, it is important that persons able to do so retain these rights, as a guardian of the person has no authority to make contracts (including leases) or to buy or sell things on the person's behalf.
- **Hold licenses.** See Section VII-C-2.
- **Associate with people of one's own choice.** A major source of conflict between guardians and wards is the person's right to choose friends and companions. Unless the person's choice of associates is likely to create a substantial risk to his or her health or safety, there is no reason for the guardian to have this power.
- **Consent to sterilization, abortion and birth control.** A person under guardianship cannot be sterilized unless the guardianship is limited to allow him or her to consent. The same may be true for abortion. If the person is able to retain control in these areas, it is useful to reserve these rights, rather than to deal with the issue later.
- **Consent to sexual contact.** This is an issue people may often want to avoid addressing. It is, however, a fundamental human right and an issue that comes up frequently. Many people under full guardianships are in fact capable of understanding and consenting to sexual contact. It would make everyone's life easier if this were determined at the outset, so that the guardian knows that his/her powers are limited.
- **Travel, and/or decide where to live.** Except in an emergency, a guardian does not have authority to force the person to live somewhere over his/her objection. Spelling out the individual's rights in this area can avoid conflicts and can also make clear the person's ability to change residence from state to state.
- **Consent to medical or other treatment.** Generally (but not always), if a person needs guardianship of the person, he or she will need some help with complex medical decision-making. However, he or she may be capable of giving consent to other kinds of treatment, such as counseling or therapy. Of particular importance may be the ability to consent to **acute inpatient psychiatric evaluation and treatment**, as guardians may lack authority to consent in this area.
- **Make or alter a will.** A guardian cannot make a will on the person's behalf. A person under guardianship will be able to execute or alter a will only if that right is reserved to him or her.
- **Have access to or release treatment and other confidential records.**
- **Limited guardianship of property.** This can be used to allow the person to retain control over wages and earnings and could be tailored to allow control over other specific property, such as Social Security payments or small bank accounts.

C. Involvement of the Individual in Decision-making After Guardianship is Created

The principle of least restrictiveness, and good practice, call for involving the individual as much as possible in decision-making even in areas where the guardian has legal authority. Such involvement is the best way for the person to learn or regain the skills needed to make his or her own decisions. In many cases "incompetence" results from lack of experience with decision-making or the need to develop more effective communication skills. Even where incompetence is likely to be long term, learning and/or cognitive stimulation can occur. Involvement is also the best way to show respect for the

person and learn his or her preferences. Finally, the person is most likely to understand and cooperate with decisions when he or she has been involved in making them.

Guardians of the estate can help the person develop financial management skills by allowing the person to handle part or all of monthly income, by use of dual-signature checking accounts, etc.

IV. PROCEDURE FOR APPOINTMENT OF A GUARDIAN

A. Petition and Hearing

Appointment of a guardian on grounds of incompetence includes the following steps:

- A relative, public official, or other interested person files a petition stating why a guardian is needed and nominating someone to be the guardian. The petition should indicate what kind of guardian is needed, and what rights and powers should be retained by the person.
 - A physician or psychologist must furnish a written statement concerning the person's mental condition, based on examination. Again, the evaluator should be asked to consider what rights the person may be able to retain. In addition, if the person (or anyone else) requests, he or she has the right to ask the court to order an independent evaluation. If the person cannot pay for the evaluation, the county must pay for it.
 - The court appoints a "guardian ad litem," who is an attorney whose job is to interview the person, inform the person of his or her rights, investigate the case, report to the court on the need for legal counsel or additional evaluation, and represent the best interests of the person.
 - If the person requests, or the court decides that justice requires it, the person has a right to an attorney to argue his or her side of the case. If the person is cannot pay the lawyer, the fees must be paid by the county.
 - A hearing is held by the court. The person must be present, unless the guardian ad litem certifies that the person is unable to attend based on specific reasons. If the person's inability to attend is related to his or her disability, the court has an obligation to provide reasonable accommodations, for example by moving the hearing to a place that is accessible to the individual. If the hearing is contested, witnesses will be called to testify on the person's competence and may be cross-examined.
-
- If there is clear and convincing evidence that the person is incompetent, the court will appoint a guardian.

B. Choice of Guardian

In choosing a person to act as guardian, the court is required to make a determination of the best interests of the person in need of a guardian. The court must consider the opinions of the person and of his or her family. Ordinarily, if a parent is suitable and willing to be a guardian, and the person does not object, then the parent will be appointed (both parents can also be appointed as co-guardians). A parent may also nominate a person by will to be appointed as guardian after the death of the parent. Finally, a person who is competent to do so can nominate, in the form of a will, someone to be appointed guardian if he or she later becomes incompetent. The court may also appoint a standby guardian, to take over if the original guardian dies or is otherwise unable to serve. The standby guardian must notify the court when he or she

takes over guardianship, but a separate hearing is not required.

The guardian should be someone who is, or is willing to become, familiar with the person's needs and situation and who will keep in frequent contact with the person. It is possible to split guardianship, appointing as guardian of the person a relative or friend familiar with the person's needs, and as guardian of the estate a person skilled in financial management.

Under Wisconsin law, a nonprofit corporation may also act as guardian, but only if no suitable individual guardian is available. The corporation must be approved by the state Department of Health and Family Services. Where there is a serious lack of individual guardians, organizations of family members or friends may want to consider offering corporate guardianship.

C. Temporary Guardianship

If a judge finds that there is an immediate need for a guardian for a person who has no permanent guardian, he or she may appoint a temporary guardian for up to 60 days, based on the petition alone, without prior notice to the person affected and without a hearing. The petition must be supported by a report from a physician or psychologist. The person must be notified of the petition for a temporary guardianship and of any court order for temporary guardianship, and has the right to an attorney and to a hearing to reconsider or change the guardianship. The temporary guardianship may be extended only once for an additional 60 days.

A temporary guardian may only perform duties specifically listed in the court order. Temporary guardianship may be useful where there is an urgent need for guardianship and there is not time to go through regular guardianship proceedings or the person is only temporarily incompetent. Unfortunately, repeated temporary guardianships are sometimes used to obtain legal consents for people who really are in need of permanent guardians. This practice deprives the person of his or her right to a full guardianship hearing, and of a guardian with a long-term interest in and knowledge of his or her circumstances and needs.

D. *Costs of Guardianship*

An attorney will usually be needed to prepare a petition for guardianship. It is probably best to call more than one attorney to ask about experience with guardianship and fees before hiring someone. Fees vary, and will be higher if the guardianship is contested. There may also be costs for medical or psychological evaluations.

Sometimes there may be no family member or other concerned person who is willing or able to pay the cost of bringing a petition. Many counties bring petitions for guardianship, but great variation exists among counties in the kinds of cases where the county will bring the petition. Where a prospective guardian requests help, some counties will charge the guardian for the costs of the petition, based on his or her ability to pay.

Counties are most likely to bring guardianship petitions where there is a need for a guardianship as part of an order for protective placement or services, or where guardianship is needed to protect the person from abuse, neglect, or exploitation. Under those circumstances, the county can consider assistance with guardianship to itself be a protective service. A possible route where this fails is to file a grievance alleging that the absence of a guardian violates rights under sec. 51.61, Wis. Stats, (see Section VII-G).

The cost of the guardian ad litem and attorney (if any) for the proposed ward may be charged to the proposed ward, if he or she can afford to pay. If he or she cannot pay, the county must pay these costs.

E. *How Does a Guardianship End?*

A guardianship continues for the life of the person found incompetent, unless it is terminated by the court. The court should review the guardianship when the person reaches the age of 18 or marries, to see if the guardianship is still needed.

In some cases, a guardianship will only be needed while the person gains (or regains) the skills he or she needs to see to his or her own needs. The person, the guardian, or any interested person may at any time petition for a review to determine if the person is still incompetent. The person is entitled to a hearing on the petition, and to be represented by a lawyer. The court must appoint a lawyer if the person requests one, and if the person cannot pay for the lawyer, fees must be paid by the county of legal settlement. After the hearing, the court can continue or end the guardianship, or can change the guardianship, for example by creating a limited guardianship.

V. POWERS AND DUTIES OF A GUARDIAN OF THE PERSON

A. Role of a Guardian of the Person

Under Wisconsin law, a guardian of an adult has "custody" of the person. The exact meaning of "custody" is not defined. The powers and duties of guardians have been defined over time by statutes and case law, and there are still gaps. Use of the word "custody" should **not** be read to mean that a guardian of an adult has the powers and duties of the parent of a child.

The guardian does not have a legal duty to financially support the person with the guardian's resources. The guardian may take the person into his or her home, but is not required to do so. Instead, the statutory duties of a guardian of the person are to:

- Receive notices and act in all proceedings as an advocate of the person (except that a guardian of the person who is not also the individual's financial guardian may not represent the person where his or her property is involved);
- Try to secure necessary care, services or appropriate protective placement for the person; and
- Report annually to the court on the condition of the ward, including where he or she lives, his or her health, any recommendations by the guardian, and a statement of whether or not the person is living in the least restrictive environment consistent with his or her needs. If the person is under protective placement, the guardian may use the county's protective placement report for this. This should only be done, however, if the guardian has independently looked at the person's situation and agrees with the report.

In making decisions on behalf of the person, the guardian is expected under the law **to act in the best interests of the person and to use the judgement and care which persons of prudence discretion and intelligence exercise in the management of their own affairs**. Put another way, the guardian should try to decide what a reasonable person would do in the situation of the person under guardianship. A guardian does not need special expertise, but does need basic common sense and a willingness to learn about the person's needs and rights, and sources of support and services.

The responsibility of a personal guardian should be seen as far more than arranging for food and a warm place to live. A guardian is responsible for seeking services that will help the person to reach or maintain his or her fullest potential, and that will allow the person to live and work in the least restrictive environment possible. The guardian is also responsible for assuring that the persons' rights and dignity as a person are defended. In order to fulfill this responsibility, a guardian of the person should:

- Learn about sources of funding and appropriate services for the person. A guardian is not responsible for providing care and services, but is responsible for knowing what is available to provide income, medical care, vocational services, etc., and for making sure that applications are filed and followed through.
- Know the circumstances and condition of the person. Knowing what supports and services are needed will mean consulting with the person, learning about the disability, and talking to professionals and others involved in the person's life. Guardians should try to attend all staffings, and should learn to ask questions and seek more than one opinion. Although the statute does not specify a level of contact, a good guideline is that the guardian should have some personal contact with the person at least every month, and a personal visit to the person at least every 3 months.

If possible, it is useful to see the person in a variety of settings, such as the home, work or day program, at a

restaurant, etc. A guardian who lives far away should arrange either to make visits or to find someone locally who can visit and report to the guardian.

- Act as an advocate for the person, not only in obtaining services but also in assuring that his or her rights are defended. This means that the guardian must learn about basic rights of people receiving services for mental or developmental disabilities and about specific rights for the person's residential setting or workplace. (See Section VII.)
- Assure that the person's freedom is not more restricted than it needs to be. The person has a legal right to the least restrictive living and service environment consistent with his or her needs. In addition, a good guardian will involve the person in all decisions and will try to give the person the opportunity to make choices of his or her own, so that the guardian exercises the least possible control, and so that the person has an opportunity to learn responsible decision-making and, hopefully, can gain greater independence. This may involve allowing the person to take some risks, but a good guardian must recognize his or her responsibility to help the person learn to be independent, as well as his or her responsibility to assure that the person has needed supports. (See next section for some way of measuring restrictiveness.)
- Remember that need for guardianship in many cases results from the fact that the person was never taught how to make choices and take responsibility. A good guardian will try to give the person these opportunities, and will seriously reevaluate whether the guardianship is still needed.

B. What is the Balance Between the Guardian's Power to Protect and the Person's Constitutional Rights?

A guardian gets his or her powers from the state. Guardianship is a creation of state laws and guardians are appointed by state courts. When a guardian exercises control over a person, he or she is acting for the state, and is subject to constitutional limits on the state's power to interfere in the lives of its citizens, as well as to state policy calling for the least possible restriction on exercise of constitutional rights. Fundamental constitutional rights are discussed in more detail in Section VII-B. Fundamental constitutional rights include the rights to life, liberty, freedom of speech and religion, freedom of association, privacy, access to government, and voting.

Where the person has an expressed wish in a fundamental area, it is arguably an abuse of the guardian's authority to ignore those wishes without a clear protective purpose for doing so. Some conflicts can be avoided by defining the guardian's powers at the outset through limited guardianship. (See Sections III and VII).

C. What Factors Determine what is "Least Restrictive"?

One responsibility of a guardian is to make sure that supports, services, placements and limits on rights are no more restrictive than necessary to achieve their purposes. Service systems often focus primarily on supervision and (hopefully) treatment. Guardians play an important role in ensuring that the person's typical human rights and needs are also considered. In evaluating whether a particular support, service or placement is the least restrictive, statutes, administrative rules and court cases have identified the following factors:

- Placement and services should, as much as possible, **integrate the person into the community** and promote relationships with a variety of people. Residential, recreational, work or program settings that separate the person from the community should be used only if it is not possible to provide the same supports justified by inability to provide needed support services in integrated settings.

- Placement and services should **place the least possible restriction on personal liberty and constitutional rights**. This factor relates to freedom of movement, discussed below, and also to other rights, such as freedom of association, freedom of religion, privacy rights, rights to hold property, and right to vote.
- Placement and services should as much as possible **allow the individual the same rights as other citizens**. If people are treated differently from other citizens, is there some compelling and unavoidable need for the difference?
- Placement and services should **least limit the person's freedom of choice**. This factor relates to the range of choices available and to the person's role in making those choices, and also to the extent that the person is helped to develop and use an effective communication system.
- Placement and services should be those that **least limit the person's mobility**. This factor relates not only to the use of physical restraints and locks, but also to programmatic restrictions on mobility, such as policies that limit freedom of movement and availability of opportunities and supports to be out and about in community settings.
- Placement and services must **minimize harm to the person's image and social standing**. Rightly or wrongly, placements in certain settings, particularly large institutions such as nursing homes and mental hospitals, cause other people to make negative assumptions about the people placed there. The principal of least restrictiveness tries to avoid this kind of harm.
- **Avoid discontinuity in personal relationships and living situation**. Not all change is bad, but loss of familiar places and people can be painful and confusing. Moves should be justified by benefit to the individual, rather than convenience of service providers.

Another way to look at least restrictiveness is the *principal of normalization*. Normalization means that in programs for people with disabilities, the goals that are established and the methods selected to meet those goals should reflect the life experiences that most community members desire for themselves. In other words, a service should be favored if it is the type that most people in society use to meet the same need: housing should be provided in a typical home or apartment; work should be done at a typical workplace, etc. Use of this test will promote integration and avoid choices which most of us would not accept for ourselves.

D. Securing Appropriate Care and Services

A guardian is not just someone who signs forms so that the person can get services and treatment that happen to be offered to the person. A guardian has a responsibility to act as an advocate for the person and to try to secure necessary care services, or appropriate protective placement for the person. Thus, the guardian must have a way to know what the person's needs are, and must try to assure that they are met. If an application for needed services is refused the guardian must evaluate whether the denial is justified or whether there should be a second request or an appeal of the denial. The guardian has full access to all of the files and records kept on the person, and cannot be denied information which is needed to check the accuracy of, or reasons for, agency decisions.

The guardian must try to get necessary and appropriate care, services, and placement, but is not ultimately responsible for providing a support or service if there is no program to provide it or if reasonable efforts fail to get the supports from programs that do exist. In deciding how hard to try and what strategies to use, a guardian again should ask him or herself what a reasonable person would do if he or she had the needs of the ward. This would vary according to the importance of the service involved and the likelihood of success. An application for funding for needed medical care should probably be worked on harder than a minor improvement in a vocational program. A guardian may decide that there is little chance of winning on an issue, and therefore that it is not reasonable to appeal a denial of services. A

guardian may also decide that pushing too hard for an issue may create hostility from service providers and others important in the ward's life, and that this will do more harm than good.

The duty to try to obtain necessary and appropriate services goes beyond simply assuring adequate food, clothing, shelter and medical care. Services will be "appropriate" only if they also support the person to engage in rewarding activities and to be as independent and productive as possible, and to gain, maintain or regain skills and abilities that will help the person be more independent. Whatever the person's level of ability, it is almost always possible to develop approaches to help the person to learn something more, or to provide stimulation and activities to help the person retain existing skills.

In recent years, there has been a shift in the philosophy of long-term care towards a "support" model. Under earlier ideas, people were often denied access to typical homes, communities and experiences until they had received "treatment" in segregated facilities that made them "ready." Unfortunately, the "treatment" often never resulted in the skills needed to meet the "readiness" test. Under a support model, the presumption is that a person should always be supported to live in his or her own community and to have normal life experiences of personal relationships, work, play, etc. This does not mean that habilitation or treatment services should not be provided, only that they should be provided in ways that also support the person to have a normal life.

Although the protective placement law requires a finding by a judge that the person's disability is permanent or likely to be permanent, this does not mean that the same level of care and residential treatment will always be appropriate. It is likely that the levels and types of protective services and placement will change many times during a person's life, as the person's needs and preferences change, or as the service system itself develops more effective ways to support people in less restrictive settings.

E. *Choosing Medical and Psychological Treatment*

1. Introduction

Personal guardians are often called on to give consent to medical, psychological or other treatment. Before a professional or agency may give a treatment, such as medication, surgery or behavioral treatment, to a person, the professional or agency must get the *informed consent* of the person. That is, the person must consent knowing the risks and benefits of the treatment, and the alternatives to the treatment. Where a person is incompetent, the guardian must

act for the person by deciding what a "reasonable person" would do in his or her situation.

There are some decisions where courts have held that the guardian does not have the power to consent for a person who cannot consent for himself or herself, including a decision to donate an organ to another person or to be sterilized. These actions may not be possible for someone who cannot give informed consent.

2. What is an Informed Consent?

To give an informed consent to a treatment or service, a decision-maker should be provided with complete and accurate information about:

- The benefits of the treatment or service, and the likelihood that it will succeed;
- The way the treatment or service will be provided;
- The risk of side effects which are a reasonable possibility;
- Alternative treatments or services, and their likely results;
- What is likely to happen if the person does not get the treatment or service.

Unless there is an urgent need for immediate action, you as a decision-maker should be given the time you need to think about what you were told, ask for more information, or seek information from someone else.

3. Customary Medical Treatment Decisions

Guardians have clear authority to consent to medical treatment that is for the person's benefit. The guardian's duty is not simply to consent to whatever is recommended: the guardian should give the same kind of careful thought that a reasonable person would give in consenting to care for himself or herself. The guardian should be sure to obtain the information needed to give an informed consent.

The amount of time a guardian will need to devote to a decision will depend to some extent on the nature of the procedure. Some medical decisions, such as the decision to follow a doctor's advice to have your appendix out, are reasonably straightforward: you can be pretty sure that you need the operation, that it will work, and that there are no other good choices. On the other hand, some decisions, such as whether to have surgery for a bad back, may be much harder: you can live with some back pain, an operation may not work, there are significant risks that you might be worse off, and there are alternative approaches, such as exercise, physical therapy, chiropractic services, acupuncture, etc., that might be worth trying first. Typically, you would want to take some time about this kind of decision, and to seek other opinions, perhaps from other kinds of professionals with other, less drastic approaches.

A guardian can play a very valuable role as historian: the guardian will often be the one constant person in medical decisions over time. A guardian should make an effort to learn the person's medical history and should tell the doctors if the ward is allergic to medications, or has a history of particular medical problems or complications.

4. Procedures that Only Benefit Others

Sometimes, a person may be asked to undergo a medical procedure to benefit other people. Where the procedure involves risk, is irreversible, and does not clearly benefit the individual, a guardian in Wisconsin probably lacks authority

to consent for the person. For example, in one Wisconsin case a guardian asked the court to approve consent on behalf of the ward to donate a kidney to the ward's sister, who had lost both kidneys. The ward in that case was not able to indicate whether he wanted the operation. The state Supreme Court held that the guardian could not consent because the operation did not serve any interest of the ward. While a "reasonable person" might have consented in the ward's situation, the court refused to allow either the guardian or a judge to use his or her "substituted judgement" to decide what the ward would have done if he had been competent. A different case might be presented if the ward had been able to indicate a strong attachment to his sister, a desire to help her and some understanding of the operation.

Another example of a procedure for the benefit of others is an experimental procedure that would increase medical knowledge but does not have any substantial chance of helping the individual patient. Again a guardian in Wisconsin probably lacks authority to consent for the ward. The statutes governing treatment facilities and agencies for people with mental disabilities specifically require informed consent from both the guardian and the ward to any experimental procedure.

5. Treatment for Mental Disabilities; Behavior Modification; "Drastic" Procedures

Except where the treatment is necessary to prevent serious physical harm to the person or others, the written, informed consent of the guardian of the person must be obtained for treatment and services that are needed due to the mental illness, developmental disabilities, or alcoholism or other drug abuse of a person who is under guardianship. Treatment and services can include: psychoactive medications, such as tranquilizers and antidepressants; behavioral treatment programs; psychotherapy; drug treatment programs; etc. The informed consent of the guardian is necessary regardless of whether the person is under an order for protective placement or commitment.

In looking at these programs, guardians should make sure that the person is provided with a positive environment and activities, and that negative or restrictive programs, such as those using restraint or seclusion, are used only in an emergency or for genuine treatment purposes, and then only when the provider has clearly shown that other more positive methods will not work. (See Section VII-G). Some settings, such as nursing homes and community-based residential facilities, have strict restrictions on use of restraints. The Bureau of Quality Assurance or the Board on Aging and Long Term Care can provide current guidelines. If a program has gone on for a long time with no change in the person, a guardian should question whether it is useful to continue the program, whether another approach should be looked at, or whether other things about the person's environment and activities should be changed.

The state's bill of rights for people in treatment facilities and agencies for people with mental disabilities specifically requires informed consent from **both** the guardian **and** the person before any experimental or drastic procedure may be used. "Drastic" procedures include psychosurgery and electroconvulsive treatment. However, the courts have found that an exception exists where the person is unable to consent, there is a threat to the person's life, and the proposed treatment is a life-saving remedy.

While the guardian has authority to consent to psychoactive medications, the guardian does not have authority to use or authorize use of force to administer medications or treatment over the person's objections. A court may authorize use of force as part of a commitment order, if it finds that the person is not competent to refuse the medication or treatment. (See Section V-H-5.)

If the person has a chronic mental illness, a court may issue a protective service order authorizing a guardian to consent to forcible administration of psychotropic medication on an outpatient basis, and authorizing law enforcement personnel to take the person in to the outpatient setting to receive the medication. These orders must meet strict criteria, including that the person have a chronic mental illness that is likely to respond to the medication, that there be a substantial probability of physical harm to the person or others, that the person be at demonstrated risk of commitment, and that

protective services be provided under a treatment plan.

6. Decisions to Withhold Life-Prolonging Treatment

One of the most difficult decisions a guardian may face is whether to authorize major surgery or painful therapies where the person's long-term chances for recovery are poor. The Wisconsin Supreme Court has defined a guardian's authority in only a few situations. Some states have held that a judge or guardian may use "substituted judgement" and decide what the person would decide if he or she were competent. The Wisconsin Supreme Court has not adopted this approach, and has required that the guardian make a decision based on the best interests of the person. The court's decisions have been narrowly focused on particular cases, but do provide some basis for guidance:

- A guardian does not have authority to refuse treatment to prolong life based on a decision that the person's life is less worthwhile than a non-disabled person's life. For example, if a person who is mentally retarded has a heart condition requiring surgery, it would be improper to deny the surgery because of a feeling that the person's quality of life was low due to his or her mental retardation. In other words, if the treatment would be given to a non-disabled person under the same circumstances, it should also be given to the disabled person. (Some states have made a limited exception to this to allow the court or guardian to consider whether the disability makes the treatment itself more painful or inhumane because the person's inability to understand what is happening and cooperate.)
- Where the person's wishes as to what he or she would want to be done in a particular situation are known, it is in the person's best interests to follow his or her wishes. However, there must be evidence of a clear statement of what he or she would want under the circumstances; general philosophical comments will not be enough. This "clear statement" might be a power of attorney for health care, living will or other written statement that the ward made while competent, or even oral statements if specific enough and reliably and credibly reported by other individuals.
- A guardian must begin from a presumption that it is in the best interests of the person to continue to live. This presumption can be overcome only in very limited circumstances where life expectancy and prognosis do not justify the pain, loss of dignity and dependence associated with the treatment, for example where a painful treatment will only prolong the process of dying for a short period, and would never allow the person to recover enough to be even temporarily free of the treatment.
- Feeding tubes are considered treatment, and the guardian may respect a person's clear statement that he or she would want them withdrawn under particular circumstances. The guardian may authorize withdrawal from a person who has not made a clear statement of his or her wishes only if the person is confirmed to be in a chronic vegetative state, and the guardian determines that withdrawal would be in the person's best interests. The guardian must first give notice to all interested persons including family members and the health care facility staff. If the individual is in any condition other than a persistent vegetative state, the guardian may authorize the removal of feeding tubes if the guardian can demonstrate "by a clear preponderance of the evidence a clear statement of [the ward's] desires in these circumstances."
- Given the uncertainty of the law, a guardian should seek court approval of a decision to withhold life-prolonging treatment in any situation where he or she has doubt about his or her authority.

7. Sterilization, Birth Control and Abortion

The Wisconsin Supreme Court has held that under Wisconsin law neither a guardian nor a judge may consent to sterilization for a person who cannot give an informed consent for himself or herself. The court noted the following

special features about sterilization:

- People have a constitutional right to be free of unwarranted state interference into decisions involving reproduction.
- Sterilization is irreversible.
- Other means of contraception are generally available for the individuals involved.
- Those providing substituted consent might be influenced to authorize sterilization by their interest in convenience and relief from responsibility rather than by the best interests of the person.
- Wisconsin has no statute governing sterilization of people unable to consent, and courts should not deal with the issue without legislative standards.

Where a person wants to be sterilized, one possible approach is to seek a limited guardianship so that the person retains the right to consent to the operation. It may be helpful for the person to have counseling on the issue, so that the decision is independent and the counselor can provide evidence that the person understands the nature, risks and benefits of sterilization.

The court does not question the guardian's authority to consent to other birth control methods, and this is the best solution for many people. If a guardian feels that sterilization is essential and the person cannot consent, he or she should first seek court approval. The court might reach a different decision in a situation where other forms of birth control could not be used and there was a significant health risk if pregnancy occurred. The court's limitations on a guardian's authority should not apply when an operation is necessary because of a significant danger to the person's life or health not connected with pregnancy. For example, if a ward has cancer of the uterus, a guardian could consent to an operation to remove the cancer even though it results in sterilization. The court's limitations also should not apply where the person can understand the risks and benefits of the operation and give informed consent. In that case, the court can be asked to limit the guardianship to allow the person to consent for himself or herself.

The Wisconsin appeals courts have not dealt with a guardian's power to consent to (or refuse) an abortion for a ward. As with sterilization, courts have found that a woman has a constitutional right to make decisions on abortion without state interference. Again, a court could limit the guardianship to allow the woman herself to make the decision where she is competent to do so. If a woman is not able to consent, and the guardian feels an abortion is in her best interests, the guardian should seek court authorization to consent to an abortion. Even if she is not fully competent, a woman's expressed preference should carry great weight in deciding what is in her best interests.

F. Making Residential Placements for Care, Treatment or Supervision

A person continues to have a constitutional right to freedom of movement even though he or she has been found in need of guardianship. (See Section VII-B-3.) Implementing this right should include involving the person as much as possible in deciding where to live, and protecting the person's right to live in the least restrictive conditions under which needed care, treatment and supervision can be provided. Because of the importance of this right, any placement to a community residential facility that a person protests, and any long-term placement to a more restrictive facility such as a nursing home or institution, must be reviewed and ordered by a court to assure that it is really necessary and that a less restrictive placement is not possible. (If the person has signed a health care power of attorney, this may give a health care agent further authority to make placements to residential facilities and nursing homes without a court order. This authority cannot be used if the person has a developmental disability or mental illness.)

The authority of a guardian to act without a court order has been spelled out in the state's protective placement law. As long as the person does not object, the guardian can consent to admission to a foster home or a community-based residential facility (such as a group home or halfway house) that has fewer than 16 beds. A guardian may only consent if the placement is in the least restrictive environment, and must review the placement each year. A guardian may also consent to admission of the person to a nursing home if the person is admitted directly from a hospital for a recovery period of up to 3 months. (This cannot be done if the hospital admission was for psychiatric care.)

If a person admitted to a community residence or for short-term nursing home care objects in any way, either in words or by other actions (for example, by trying to leave physically), the facility has an obligation to inform the county protective services agency, which must investigate as soon as possible (within 72 hours at most.) If the protest continues, the placement must either be ended or a protective placement order must be obtained from a court.

G. Admitting the Person for Psychiatric Hospital Care

Although there are state statutes that allow a guardian to make short-term admissions to a psychiatric hospital, the Wisconsin Supreme Court has held that a guardian does not have authority on his or her own to authorize admission of the person for inpatient psychiatric treatment in a hospital. The person can be voluntarily admitted only if both the guardian **and** the person give consent.

The statutes provide that if a person refuses or is unable to consent but does not actively object to admission, he or she can be admitted for up to seven days as a "voluntary" patient, if the physician certifies that the person has been informed of the benefits and risks of treatment, of his or her right to request release, and of his or her right to the least restrictive form of treatment appropriate to his or her needs. A court must be notified, a guardian ad litem must be appointed, and there must be a court hearing after 7 days.

In other situations, particularly where the person objects to the admission, a civil commitment must be ordered by a court to require involuntary psychiatric treatment. (See Section V-H-5.) If there is an emergency that involves a substantial risk of physical harm to the person or other people, a law enforcement officer may take the person to a hospital, which can admit the person without consent for up to 72 hours. The person can be held pending a commitment hearing a court finds probable cause that the person meets commitment standards.

H. Court-Ordered Services and Placement

1. The Protective Service System

Chapter 55 of the Wisconsin Statutes establishes a protective service system designed to prevent abuse, neglect and exploitation of people with long-term mental disabilities, while at the same time trying to ensure that as far as possible they keep the same rights as other people. The statute requires each county to designate an agency to plan the local protective service system.

The protective service and protective placement laws are intended to protect people with developmental disabilities, chronic mental illness, mental and physical disabilities caused by advanced age, and similar disabilities, if the disability substantially impairs the person's ability to meet their basic needs. Anyone who has a guardian based on a finding of incompetence should be eligible for protective services. Depending upon the individual, protective services or placement can mean everything from some counseling or arranging for help with homemaking to placement in a residential facility or institution against the person's will.

In an effort to prevent exploitation or abuse of old and disabled people while at the same time making sure that the "protectors" did not go overboard in their protective efforts, the law requires that the protection be provided in a way which places **the least possible restrictions on personal liberty and exercise of constitutional rights**. Although the system allows for involuntary placement in residential settings, the statute requires that the system encourage independent living and avoid protective placement whenever possible. If a protective placement is ordered, it must be to the least restrictive environment consistent with the person's needs.

Under the law, services to the person in his or her home should be used to avoid protective placement whenever possible. The law prefers that protective services be provided at the request of the individual or, at least with the voluntary cooperation of that person. A guardian can authorize services for a person who cannot consent, provided that the person does not resist the services.

Protective services can only be provided to a person against his or her will in those situations where there first has been a court finding under the guardianship laws that a person is mentally incompetent and secondly that there has been a court finding that the person will incur a substantial risk of physical harm or deterioration if the services are not provided. A county protective service agency can provide involuntary service on an emergency basis, without specific court order, when it appears that the person entitled to the services or others will incur substantial risk of serious physical harm. Emergency services may not be provided for more than 72 hours. For involuntary services after that point there must be a court finding of probable cause that the person meets standards for a protective service order.

The law requires a court finding of incompetence under the guardianship law before protective services or placement can be ordered. If the court finds that the person is competent to make his or her own decisions, services cannot be forced on the person, even though he or she is choosing to lead a life that seems "strange" or different from the way other people want him or her to live, and even though he or she might really benefit from the services. (If a competent person is at risk of harm and needs treatment, he or she may be subject to a commitment. See V-H-5.)

If the court finds that the person is mentally incompetent to make those decisions and also that some form of protective services is needed, the next step is to evaluate what the person's needs for protection are and then order only those services which place the least possible restrictions on the person's freedom and lifestyle. An example of this would be that of a moderately mentally retarded adult who has quite a few of the skills necessary to live in the community (e.g., can meet his self-care needs and get around the community safely) but still lacks skills in preparing a menu, cooking a meal, and handling large amounts of money. Since a combination of protective services, such as home-delivered meals, a temporary representative payee, counseling and training in money management and education in menu planning would be a way of meeting all this person needs, the law should not authorize a residential placement which would take more personal freedom away than is necessary.

2. Protective Placement

As discussed in Section V-F, a guardian can only consent to placement for a person where the placement is in a foster home or group home, or is temporary, and where the person does not object. Except in situations governed by a health care power of attorney, a court order for guardianship and protective placement is required for long-term placement of an incompetent person in an institution or nursing home, even if the person does not make any objection. Court review and continuing oversight is provided to ensure that placement of a person who cannot consent is meeting the person's needs and is not more restrictive than absolutely necessary.

A court can order protective placement only if it finds that:

- The person has been found to be mentally incompetent under the guardianship laws (often, the guardianship and protective placement processes are combined);
- The person has a disability which is permanent, or likely to be permanent;
- As a result of the disability, the person is so totally incapable of providing for his own care or custody as to create a substantial risk of serious harm to the person or others. Serious harm may be proved by either showing what the person does or what the person fails to do; and
- The person has a primary need for residential care and custody, that is, the person's needs could not be met through services alone or through short-term treatment.

The person is entitled to notice of the hearing and to appointment of a **guardian ad litem**, who is an attorney who interviews the person and informs the person of his or her rights, investigates his or her needs and circumstances, and makes an independent report both as to what rights the person and guardian want to exercise, and also as to the guardian ad litem's own recommendations concerning procedural rights and appropriate placement. The guardian ad litem should always talk to the guardian of the person where one has been appointed, to find out the guardian's position on the placement and to find out if the guardian recommends that the person have an independent evaluation or an independent attorney. The guardian ad litem's responsibility throughout the process is to make sure the person's rights are respected and to advocate for the person's best interests. The guardian ad litem need not take direction either from the person or from the guardian of the person concerning what will be in the person's best interests.

If the person asks for one, or contests the need for or nature of the proposed placement, he or she has a right to an attorney to represent his or her point of view. This attorney is sometimes called **adversary counsel**. The county is required to pay the attorney's fees of the adversary counsel if the person is indigent. The adversary counsel is supposed to represent the person and his or her legal rights, and, like the guardian ad litem, need not take direction from the guardian if he or she feels that the guardian's goals are contrary to the person's rights. However, in many cases adversary counsel will listen to and follow guardian recommendations, particularly if the person and the guardian are in agreement, or the person has limited ability to communicate.

After receiving a petition for protective placement, the court must order a **comprehensive evaluation** of the person. Usually, the county protective service agency is responsible for carrying out or coordinating the evaluation. The evaluation should cover all aspects of the person's support and treatment needs and service history, and should make a recommendation for least restrictive placement, if placement is recommended. The comprehensive evaluation is an important part of the process, and the guardian should identify the person preparing the report to ensure that he or she is aware of the person's needs, preferences and history. If the report is inaccurate or incomplete, the guardian can request that the court order further evaluation.

The person also has a right to an **independent evaluation** as to any issue involved in a protective placement case, including need for placement and what kind of placement and services should be ordered. The guardian ad litem is responsible for finding out if the person or guardian wants an independent evaluation, and for informing the court of any request. If the person cannot afford to pay for an evaluation that is ordered by the court, the county protective service agency must pay for it. If the guardian believes independent evaluation is needed, he or she can ask the guardian ad litem to recommend it, or can write to the court directly. It is usually a good idea for the written request to identify by name an evaluator who knows the issues the guardian wants addressed, and to contact that person to make sure he or she is willing to do the evaluation has needed information.

In practice, a major weakness in protective placement hearings is the lack of specific evaluation of the person's needs and what type of program could meet those needs. For example, it is not uncommon to find a recommendation that says that a person "needs" a nursing home, with no explanation of what specific support services the person needs and why those support services cannot be delivered in a community setting. A guardian often knows the person and his or her history well, and can play an important role in assuring that evaluations look at the individual needs of the person and how those can be met in the least restrictive way.

Some hearings on protective placement are short, while others can be long and complicated. The person and guardian must get notice of the hearing, and the person is supposed to be present if that is possible. The hearing can be held where the person is placed if that is necessary. The person should not be excluded from the hearing just because being there would be unpleasant or stressful. The guardian also has a right to be present and to participate as a party. There is usually an opportunity for the guardian to state his or her views, if the guardian requests. Often, the guardian will be able to work closely with the guardian ad litem and/or the adversary counsel to make sure evidence is presented. However, the guardian has a right to an attorney of his or her own, and has a right to present evidence and ask questions of witnesses.

If the judge decides after the hearing that protective placement is needed, he or she will order the responsible county protective service agency to make the placement. The judge can make specific orders about where the person may be placed and what kind of services he or she must receive. The placement must be both consistent with the person's needs for support and treatment, and carry out the person's right to the least restrictive setting. (See Section V-C.) Placements are not limited to nursing homes and institutions: they can be made to the person's own home or apartment, to adult family homes, and to community-based residential facilities as well. The judge is not limited to specific placements that already exist: he can order the county to do planning and implementation to develop a needed placement. For example, a court can order the county to develop a plan to support the person in a home setting, and then to seek providers who are willing and able to provide the services.

A protective placement order **may not be used to place a person to an acute psychiatric unit** in a hospital. Such placement must either be voluntary (See Section V-G) or made through civil commitment procedures.

The county has primary responsibility for making sure that the placement continues to be appropriate to the person's needs and is least restrictive. If a **transfer of placement** is proposed, the person and the guardian must receive notice. If possible, the notice should be in advance. If the guardian, the individual, the individual's attorney or other interested person objects to the change in placement, then there must be another court hearing to determine if there is probable cause that the transfer will be in the person's best interests.

3. Protective Placement Reviews

Whenever the individual, guardian, attorney, or county agency is of the opinion that the reasons for continuing the protective services or placement no longer exists or that the person is entitled to a less restrictive or more appropriate placement, they may file a petition with the court to get another hearing on this matter and to request that an attorney be appointed to represent the person.

The county protective service agency must submit a **written review** of the person's physical, mental and social condition at least every twelve months. (The Judge may order that they be conducted more frequently.) This should provide current information on the same issues as are covered in the comprehensive evaluation, including a review of whether the person needs placement and whether the current placement is consistent with his or her needs and is least restrictive. If the guardian has concerns about the placement, he or she should specifically request input into the report.

A 1985 Wisconsin Supreme Court decision held that the court making the placement must perform an active review of the placement at least every year. This annual review is called the **Watts review**, after one of the women involved in the original case. Every year, the court must appoint an attorney as guardian ad litem to meet with the person, review the annual report of the protective service agency and inform the person that he or she has a right to request an attorney, an independent evaluation and a full hearing on the appropriateness of his or her placement. The guardian ad litem can also request an independent evaluation and can look at other records and information about the person. He or she must then report to the court on whether protective placement is still needed, whether the current placement is the least restrictive consistent with the person's needs, and whether the individual or guardian is requesting a change in placement, appointment of an attorney, or a full hearing. The guardian ad litem must contact the guardian for his or her views on all of these issues, and this is a good opportunity for the guardian to have input to the court and to suggest other sources of information for the guardian ad litem.

The judge must review the report of the guardian ad litem and decide whether to order additional evaluation, whether to appoint an attorney for the person, and whether to hold a full hearing. A full hearing must be held whenever the person, the guardian or the guardian ad litem requests it, or whenever the guardian ad litem indicates that the placement is no longer needed or is not the least restrictive possible. Again, as discussed above, the guardian has a right to participate in the hearing as a party.

4. How Do Funding Issues Affect Protective Placement?

For people who do not have enough income and resources to pay for placement themselves, the county is responsible for paying the costs of protective placement. There is no separate state funding for this, and counties must use other human service funding or local tax dollars. The result has been a strong incentive for counties to place people in nursing homes and other institutions funded by Medical Assistance, even where this is more expensive and less appropriate, because this funding does not come out of the county's budget.

Prior to 1995, Wisconsin courts had held that courts and counties could not consider the source of funding in deciding what placement was most appropriate and least restrictive. However, in December, 1995, a new law went into effect which provides that rights to least restrictive and appropriate services are limited to what the county can achieve with available state and federal funds and required matching funds. This allows counties to argue that a more appropriate placement should not be ordered because implementing it would cost county dollars.

The new law does not apply to people who met the standards for protective placement before it went into effect. Where it does apply, it should be up to the county to show that there really are no state and federal funds that could be used for a needed placement. It may not be constitutional to limit the court's power to ensure that a placement is not overly restrictive, and there is also a good argument that unnecessary segregation violates the Americans with Disabilities Act. Where this is an issue, the guardian should consult an attorney for more advice.

5. Commitment

Under the civil commitment laws, a judge may involuntarily commit a person for treatment who is mentally ill, drug dependent, or developmentally disabled, who is a proper subject for treatment, and whose actions present a substantial probability of physical harm to himself or herself or others. Commitment is generally used to provide psychiatric treatment or evaluation, either on an inpatient or outpatient basis, to a person who is resisting treatment or is unable to consent. The person alleged to need commitment has rights to an attorney, an independent evaluation and a full due process hearing. A mentally incompetent person should also have a guardian ad litem to represent his or her interests.

I. *Checklist for Guardians of the Person*

1. Annually

- a. File a report with the court and with the county protective service agency [880.38(3)] (Check with county agency for reporting requirements.) The report must, at a minimum, include:
 - (1) The location of the person.
 - (2) The person's health condition - including major health events that occurred during the year such as surgery, strokes, changes in treatment, etc.
 - (3) A statement of the least restrictive environment that the person could reasonably live in while receiving appropriate services or supervision on an in patient or outpatient basis.
 - (4) A statement as to whether the person is currently living in the least restrictive environment.
 - (5) A statement of all services which the person appears to need but is not receiving. A description of reasons why the person is not receiving services such as lack of money, denied admission, refuses to participate.
- b. Review the residential placement (if any) regarding adequacy and restrictiveness. Attend staffings for residential and day services.
- c. If there is a protective placement, review the county protective services report and make recommendations to the guardian ad litem and the court on whether an independent evaluation is needed, an attorney should be appointed, or a hearing held to review the placement.

2. Monthly

- a. Keep notes on personal visits with the disabled person:
 - (1) How is the person's physical health?
 - (2) Does he/she seem happy?
 - (3) What special things have happened since your last visit?
 - (4) Did he/she have a chance to let you know about any problems? Were there any?
- b. Keep a file of letters and notes of calls or meetings with others responsible for providing services.
- c. Keep a list of things that need to be done or questions that you want to ask:
 - (1) What is the question, concern or suggestion?

- (2) Who do you need to write to or talk with?
- (3) What has been done by you or them since last month?
- d. Regularly ask to see the records that service providers keep about the person. This should provide a summary of what is happening and how the person is doing. By making this routine, you should avoid any problems when you have a particular reason or concern that you want to check on.

VI. GUARDIANSHIP OF THE ESTATE

A. *What is the Responsibility of a Guardian of the Estate?*

Guardianship has its origins in efforts by the government to look after an individual's land, money, and other property. Usually there were two reasons for appointing a guardian. The first was to make sure that the person would not mismanage or give away all of his property and wealth so that he or she would become dependent on the government for support (and unable to pay taxes). The second reason was to allow the person's relatives to protect the land and possessions. Since these relatives were likely to inherit whatever the person had when he/she died, the use of guardianship was often used by them to protect their own self interests as well as the interests of the supposedly incompetent person.

The emphasis on guardianship for the person's property (this includes land, real estate, *and* also personal property ranging from jewelry, furniture, cars, and stockholdings through clothing, books, pictures and cash) was carried over into Wisconsin. Most of the states, including Wisconsin, have laws which talk more about the duties of guardians of the estate to take care of a person's property than about the duties of guardians of the person. While there are a number of rules that have to be followed fairly carefully in managing the person's property, the basic guideline to remember is to **always be at least as careful with all the property of the ward as a reasonably careful person would be if it were his or her own property.**

You may be personally responsible if you fail to take reasonable care in managing the person's property or finances, and this results in some loss of property or a failure to get access to income or benefits to which the person was entitled. In some situations where a lot of property is involved, the judge may require you to post a bond to ensure that the ward will be able to recover from the bond or insurance company.

An example of the guardian's level of responsibility would be a situation where the disabled person has some personal belongings - for example, a television set, winter clothes, some mementos, books, and records - that need storage for a period of six months. The guardian should consider what a reasonable and careful person would do: find a place where they would not be likely to be stolen or damaged. If some of the things were really valuable the guardian may want to make sure that there was some kind of insurance. If some or all of the things in storage were accidentally damaged, the guardian would not be legally responsible as long as his or her choice of a place to store the property was found to be reasonable.

This same guideline would be used in dealing with the person's money. As a guardian, you are responsible for making sure that whatever money that he or she has is used wisely and only for the person's own benefit. The primary responsibility is to see to the ward's best interests, not to build up his or her estate. In other words, the ward should live at the standard of living he or she can reasonably afford, while still keeping a reasonable level of funds for future needs.

The guardian does **not** have the responsibility to support the ward out of the guardian's own money. However, the guardian does have the responsibility of making sure that applications are made for all local, state, and federal income support programs (such as Unemployment Compensation or disability benefits, Social Security, Supplemental Security Income, Food Stamps, Medicare and Medical Assistance, and other supportive programs such as the Community Options Program) that could assist in supporting the ward. If the ward does qualify for these programs, it is the guardian's duty to make sure that these benefits are used wisely and that the ward does not do things which would jeopardize eligibility.

Example: Paula has no income or health insurance, is unable to work in a substantial job because of her disability, but is able to live on her own if she has the necessary money and supportive social services. She would most likely qualify for the SSI program and also for subsidized medical services through the Medical Assistance Program. It is the guardian's job to make sure that Paula rents or shares an apartment that she can afford on her income while having enough money left over for necessary food, clothes, personal items and transportation during the month, and that applications are made for needed benefits. If Paula ends up paying for some medical expenses because application for Medical Assistance was never made, a guardian might be held personally responsible for the costs.

There might occasionally be conflicts between the guardian and the ward in situations where the guardian feels that funds must be kept for basic food and shelter, and possible future needs, while the ward would rather have new clothes or more spending money. If the person really does not have extra funds, the guardian has a responsibility to ensure that the rent is paid and the person has enough to eat. On the other hand, there is an added feeling of self worth that often comes with wearing new clothes and having some money to spend as a person wishes. The person should not be kept in needless poverty while funds accumulate.

In some cases the person may have very little discretionary income because he or she is living in a nursing home or other residential setting and receives only a personal needs allowance. Even though the amount of money may seem like very little to the guardian, this does not mean that the guardian should be any less careful in how the money gets spent. The guardian must again place him or herself in the position of the ward and ask the question: "If I only had \$65 this month, what would I most want to spend it on?" The guardian should find a way to determine what the person needs or might like so that the funds can be used for his or her benefit. This might mean small expenditures each month, or it might mean saving the money for a big event or major purchase.

In all cases, the guardian of the estate is required to keep good records of how much money or property was received and how it was spent or disposed of. When first appointed, the guardian will have to prepare a list of all the ward's property along with an estimate of what each item is worth at the time the list is made (as opposed to what the item cost when it was bought). This list is called an **inventory**.

The guardian will also have to keep track of how much money was received (with the date it was received) and how it was spent. It would be a good idea to get a notebook to write all this in since there must be reports filed with the probate court each year. Ask for separate receipts when buying things for the ward and keep these receipts (write on the back of the receipt what it was for) so that it is easier to fill out the annual report.

One of the most commonly asked questions is: "Can a guardian pay him or herself out of the ward's money?" The answer depends on what the money is being paid for. Naturally the guardian is never authorized to spend the ward's money where the person is getting no real benefit. The guardian who wants to use the ward's money to buy a new coat or fishing pole for the guardian better look somewhere else for the money. A more difficult decision would be whether the guardian can charge the ward room and board or whether the guardian can charge the ward for the costs of driving

the disabled person from place to place. If the guardian is the ward's representative payee under certain government benefits, he or she might want to talk with someone at the local Social Security office about this.

In general, the guidelines should be whether you would (or have) made other adult sons or daughters, friends, or relatives pay for these kinds of services or whether these services are out of the ordinary. For example, if the guardian takes the disabled person out for a Sunday drive along with the rest of the family, it would be unfair to charge the expenses to the ward. But if the guardian had to drive a number of miles out of the way each day to transport the ward to and from a therapist or a day program, then this is probably a fair charge. (A record detailing the mileage and the expenses should be kept.) But again, ask yourself whether you would have expected a non-disabled friend or relative to pay in similar circumstances and be prepared to justify your charges to the court.

A guardian can use the person's property to pay for reasonable expenses for keeping track of the ward's property (for example the cost of using an attorney to help fill out annual forms) and for managing the property-stockbroker, investor, or real estate manager.

The word fairness is what is really important here. Most questions can be answered if the guardian places him or herself in the shoes of the ward and asks whether it would be fair to be charged for this or that. Since the guardian is also the protector of the ward, the guardian should be especially careful to avoid situations where the answer to this question is "iffy."

Perhaps more common situation for many guardians is the case where the ward's income does not seem to be enough to adequately take care of all the ward's needs. Even after the guardian applies and gets eligibility for all the possible programs for the ward, there still may not seem to be enough. At this point the guardian must again realize that just because he or she was appointed guardian does not mean that there is a legal responsibility for contributing to the ward's support.

While knowing that they have no legal duty to do so, some guardians decide to help out their ward on either a special or regular basis. When doing so it is important for the guardian to be clear as to whether the assistance is a gift or a loan. A gift is something that you do not expect to be paid back for. A loan is when you let someone else have the use of money or something else with the understanding that it will be returned to you at some point.

Because the guardian should always be careful to avoid all situations where it might look to others that he or she is trying to take advantage of the unsuspecting ward, loans with any interest charges should never be made between the guardian and the ward. This does not mean that a guardian cannot plan to pay him or herself back after lending the ward money to replace a lost or badly torn coat in the middle of winter. It just means that the guardian should avoid even the appearance of making any money off the deal.

Like a guardian of the person, a guardian of the estate should recognize that the person can only learn to manage his or her own affairs by participating in decisions, making choices on his or her own, and taking some risks. A guardian of the estate can and should involve the ward in managing some or all of his or her finances, by talking to him or her about decisions and by allowing him or her to make his or her own choices, e.g., by giving the person a weekly or monthly

allowance for expenses, or by setting up a dual checking account that allows him or her to write checks with the guardian's approval.

A guardian may not make gifts of the ward's property except in very narrow circumstances. Generally, the guardian may not make gifts because it is the guardian's responsibility to "preserve and protect" the estate. Giving away the property does not "preserve or protect" the estate. This is true even where the ward had previously, when competent, made gifts of some of his or her property, such as checks to certain charities or family members.

The law does, however, permit a guardian to use the ward's funds to pay for the "suitable education, maintenance and support of the ward and of the ward's family" **but only for family members who are legally dependent upon the ward for support**. This means that a guardian can use some of the ward's money to pay for some household expenses of the ward's spouse or minor children, but not for an elderly ward's adult children.

A second exception is that a guardian of a *married* ward (whether the guardian is the ward's spouse or not) may file a petition with the court seeking permission to use some of the ward's funds to pay for items or expenses that will benefit the ward's spouse or members of the ward's immediate family. Note that this is only for married wards and only after first receiving court permission.

B. Legal Requirements of a Guardian of the Estate

The following listing provides the four categories of laws governing Guardians of the Estate: (1) What Guardians of the Estate must do with the ward's property; (2) what Guardians of the Estate may do with the ward's property without approval of the court; (3) what the Guardian of the Estate may do with the property of the ward only with specific approval of the court; and (4) what a Guardian of the Estate may not do.

1. What a Guardian of the Estate *MUST DO*

- File the inventory of assets within six months of appointment. The inventory must be verified by the court.
- Possess the ward's property and exercise rights over it. (Title, however, remains with the ward.)
- Protect and preserve the ward's property.
- Carry out his or her **fiduciary** responsibility to exercise good business judgment and common sense. In handling the ward's assets, the guardian must use the same degree of judgment and care that persons of ordinary prudence, discretion and intelligence would use in handling their own assets under similar circumstances. Because of the duty to protect and preserve the property, a guardian may not make gifts of the ward's property, even where the ward previously had a history of doing so. Similarly, the guardian may not spend assets on items that are not solely for the benefit of the ward. For example, where the guardian and ward lived together in the guardian's home, and the guardian's roof needed repairs, the guardian may not use the ward's assets to repair the roof. (A guardian could, however, with the court's permission, charge the ward a **reasonable** rent for living there.)
- File annual accounts each year by April 15 for the preceding year. (This does not apply to corporate guardians.) The guardian must account for all funds received and spent, and is at risk of being removed by the court for failing to file these accounts.

2. What a Guardian of the Estate *MAY DO WITHOUT APPROVAL OF THE COURT*

- Demand, sue for, collect and receive all debts and claims for damages due the ward.
- Retain the ward's personal or real property possessed by the ward at time of appointment or later received by the ward by gift or inheritance without regard to Chapter 881 of Wisconsin Statutes (Trust Fund Investments), and use judgment and care as a person with prudence, discretion and intelligence, without speculating.
- Sell, invest and reinvest the proceeds of the sale of any trust fund investments according to the law in Chapter 881 of Wisconsin Statutes.
- Settle all the accounts of the ward.
- Use the personal property or income of the ward for the suitable education, maintenance, and support of the ward and family members. (NOTE: This includes spouse and dependent family members only.)
- Use the personal property or income for the care and protection of real estate (or real property) owned by the ward.
- Collect the ward's income, such as Social Security, pension, dividends and interest.
- Pay the ward's bills and contest or compromise claims.
- Take care of the ward's home or other real estate and put things in storage.
- Hire professionals (for example, attorney, CPA, appraiser, etc.)
- Sign the ward's tax returns.
- Petition for placement of the ward's assets into his or her revocable living trust.
- Apply for public benefits, e.g., SSI or Medical Assistance. NOTE: In anticipation of such application, the guardian may purchase irrevocable burial trust, paid-up life insurance and other exempt assets for the ward. There is, however, no authority for the guardian to divest the ward's assets.

3. What a Guardian of the Estate *MAY DO ONLY WITH SPECIFIC PRIOR APPROVAL OF THE COURT*

- Continue the business of the ward. The court must decide that continuing the business is advantageous to the ward and then set terms and conditions of how the business would be continued.
- Invest proceeds of the sale of any property or funds subject to the guardianship in other real or personal property. Any such investment must be determined by the court to be "in the best interests of the ward."
- Keep any real or personal property of the ward possessed by the ward at the time of appointment or received by gift or inheritance **when prudent business practice would suggest that the property be sold and the proceeds invested.** (EXAMPLE: A guardian should ask for court approval to hold on to an antique family heirloom to avoid a claim of mismanagement of the estate.)
- Sell, mortgage, lease, or exchange any property of the estate, and then only for:
 - Paying the just debts of the ward; OR

- Providing for the care, maintenance and education of the ward or the ward's dependents; OR
- Investing the proceeds; OR
- Any other purpose the court determines to be in the ward's best interests. **NOTE: Very specific, detailed procedures must be followed and the advice of a lawyer is recommended.**

4. What a Guardian of the Estate *MAY NOT DO*

- Loan any of the guardianship funds to him or herself.
- Use any of the guardianship funds or property for his or her personal needs.
- Give away or donate any of the ward's funds or property, even where there has been a pattern of such gifts, or to assist the ward in qualifying for Medical Assistance.
- Purchase any of the property of the ward unless:
 - the sale is a public sale, such as an auction; AND
 - the court specifically authorized the sale; AND
 - the guardian making the purchase is a spouse, parent, child, brother, or sister of the ward, or is a co-tenant with the ward in the property.

NOTE: A Guardian of the Estate has no authority over personal and health care-related decisions for the ward, such as consenting to health care or deciding where the person should live. Generally, a guardian of the estate should not use his or her power over the person's funds to control personal decisions. For example, a guardian of the estate can refuse to sign the lease for an apartment that the person cannot afford. On the other hand, the guardian of the estate should not refuse to sign a lease as a way of controlling where the person chooses to live, or refuse to release personal needs funds as a way to force the person to accept treatment.

VII. PRESERVING AND PROTECTING THE PERSON'S RIGHTS

A. Introduction

A goal of Wisconsin's protective service and guardianship statutes is to allow the person, as much as possible, the same rights as other people have. In addition, people in service settings, such as mental health treatment or nursing homes, have special rights in relation to service providers. It is important for a guardian to understand the person's rights and to look at them from at least three points of view:

- What rights are the person still able to exercise safely and effectively for him or herself? There is no reason for a guardian to take over these rights, and they should be reserved for the person through a limited guardianship. (See Section III) Are there other areas where a guardian is needed to prevent harm or protect a right, but the person can be involved in the decision, to give him or her as much autonomy as possible, and to help him or her learn to exercise the right?

- What rights create limits on the guardians powers to direct the person's life?
- What rights is the guardian responsible for protecting and promoting as part of the duties of a guardian?

B. *Constitutional Rights*

1. Balancing Constitutional Rights with the Guardian's Responsibility to Protect the Person's Best Interests

A person who is under guardianship does not lose his or her constitutional rights. Constitutional rights protect individuals in our society from undue interference by the government. Among these protected rights are: the right to life; the right to personal liberty; the right to freedom of speech and religion; the right to associate with persons of one's own choosing; the right to due process of law; the right not to be subjected to cruel and unusual punishment; and the right to have access to the government and the courts.

Because a guardian gets his or her powers from state statutes and the order of the court, he or she is considered to be acting for the state when making decisions that limit the person's constitutional rights. Put another way, the guardian has no more power to interfere with these rights than the state has under the constitution.

The ordinary rule is that the state must show **a compelling need for interfering with constitutional rights**. This same test can be useful for guardians: if a guardian's exercise of his or her powers will interfere with the person's constitutional rights, is there some compelling reason, such as physical safety or protection from abuse and neglect, that justify the interference? For example, a guardian probably has the authority to prevent the ward from having contact with someone where there is good reason to believe that the other person would physically abuse or financially exploit the person. On the other hand, it is probably an abuse of the guardian's powers to prevent the ward from seeing certain friends because the guardian does not like them or because it is inconvenient.

The guardian's power probably varies with the ability of the person to make his or her own decisions and express his or her preferences. The more clearly the person is able to state a preference in a protected area, the more this preference should be respected. For example, a guardian may be able to take a person to the church of the guardian's choice if the person agrees or states no opinion. On the other hand, a guardian should not use his or her powers to pressure a person to attend a particular church if the person protests because he or she clearly prefers a different religion or no religion at all.

Because mutual respect and a cooperative relationship are more likely to help the person learn responsibility than overuse of power, the guardian should carefully weigh the person's abilities and preferences and the level of danger to the person's interests before using his or her legal authority to control the person's life. Where a guardian is considering acting to restrict the person's basic rights as a citizen, the guardian should consider several factors:

- What level of risk is typical in our society in order for people to have typical life experiences? Is the person losing out on having a normal life when he or she is not in significantly more risk than the rest of us? We all make mistakes - and hopefully learn from them. People under guardianship should have this same "dignity of risk," if it can be done without exposing them to a substantial risk of serious harm.
- Are there ways to protect the person other than completely taking a right away? For example, if there are concerns about a particular visitor, can visits be monitored rather than prohibited?
- Can the person learn to exercise the right by being given controlled opportunities to make his or her own decisions?

As stated earlier, the guardian's role in having custody over the person is to care for the needs and rights which the

person is incapable of taking care of on his/her own. Taking power over areas where the person does not need help can be as harmful as not providing support where it is needed.

2. The Right to Life

A person's right to live is in no way lessened because of a mental or physical disability or because they are a ward under a guardianship. To some people, this last sentence may seem too obvious to need to be said, but historical review of society's treatment of disabled people indicates numerous instances where a decision was made to not provide disabled people with available medical treatment and, therefore, that person was allowed to suffer, deteriorate, or die. The guardian has a duty to make sure that the ward's medical needs are provided for just as they would be for people without disabilities. (See Section V-E-6)

3. The Right to Freedom of Movement and Choice of Residence

Responsibility for the person's care and custody carries with it responsibility to ensure that the person does not place him or herself in unsafe situations, for example by going out in traffic if the person does not understand the risk, or going out in bad weather without adequate clothing. On the other hand, the law is not at all clear as to the level of physical force that a guardian is authorized to use. For example, the courts have held that a guardian may not authorize physical force to make the person accept psychotropic medication. This may also apply to use of force to make the person go to a treatment or other service setting. In practice, without clearer guidance from the law, guardians must try to use common sense. If there is a consistent use of physical force needed, or if the person is confined through use of restraints or locked doors, there will usually be a need for some kind of court order for protective services or commitment.

As discussed in Section V-F, the guardian does not have the authority to require the person to live in a residential placement against the ward's will, or to place the person in long-term nursing home or institutional care.

If the person is capable of choosing his or her own residence, with or without advice from others, it may be useful to specifically reserve this right through limited guardianship, so that it is clear that this is not a responsibility of the guardian.

4. The Right to Freedom of Speech and Religion

In applying the Constitution, courts have been very strict about protecting the right of all individuals to express themselves and choose their own religion - or choose not to practice any religion. It is difficult to imagine a situation where the court would, because of a person's mental disability, authorize anyone to restrict the person's right to express themselves.

Courts have agreed that some individuals will have a more difficult time reaching their audience because their right to liberty has been restricted after following due process. Yet, even in situations where a person is involuntarily confined to a residential facility, the courts have been careful to make sure that the rights of such persons to receive visitors and mail and to write letters or telephone others is respected. For example, it may be acceptable to limit the number or timing of telephone calls, so long as the person's basic right to communicate with others is not denied. The law is particularly protective of the right to communicate with the courts, government officials, and attorneys. See Sections VII-F and G for rights of individuals in Wisconsin residential and treatment settings.

5. The Right to Associate with People of the Person's Own Choosing

There are at least two parts to the right to associate with other people: 1) the right to have friends and to develop relationships with people who are meaningful to you; and 2) the right to elect not to associate with persons who you do not like or who would likely harm you or take advantage of you.

A mentally disabled person might have communication or other problems which will make it more difficult to establish and maintain friendships. While the guardian does not have an obligation to make sure that the person has friends, it is certainly within the scope of the guardian's role to assist the person in developing friends, to put the person in situations where friendships can occur naturally, such as work or recreational activities, or even to encourage the ward to spend time with certain people.

Choice of friends and associates is a frequent cause of friction between guardians and wards. Sometimes, the person will be in real danger from a person who abuses the person physically or sexually, or uses pressure or fraud to take money or property the person requires to live on. However, in other cases the guardian may be expressing his or her own likes or dislikes, or trying to eliminate even normal risks because then the guardian will not have to worry about those risks.

If the person is able to choose his or her own friends, perhaps with some advice from others, it may help to avoid conflict to reserve this right through a limited guardianship. By not taking on this power to begin with, the guardian can avoid feeling responsible for risks the person may encounter.

6. The Right to Privacy; Reproductive and Sexual Rights

Constitutional rights to liberty and privacy have been held to include rights to control one's own body, such as the right to control reproduction and the right to private sexual activity between consenting adults. The role of guardians in issues of medical and other treatment, birth control, sterilization and abortion is discussed in Section V-E-7.

The issue of whether the person can consent to sexual contact is very important. **Sexual contact with a person who is unable to consent is a criminal sexual assault**, and the guardian clearly has a right and duty to prevent such sexual contact from occurring. A person is incapable of consent under the law if he or she has a mental disability that makes him or her incapable of appraising his or her conduct. If the person is not able to consent, the guardian does not have the authority to give consent to sexual contact on the person's behalf.

While Wisconsin law does not set out a clear test, tests which courts have applied to determine ability to appraise conduct include:

- Does the person understand that certain behavior is sexual?
- Does the person understand that he or she has a right to say no to unwanted sexual contact?
- Is the person aware of the consequences of sexual contact?

The fact that a person is under guardianship does not answer the question of whether he or she can consent to sexual contact. The standard for guardianship (incapable of care for self due to mental incapacity) is different from the legal test for consent to sexual contact, and in practice there are many people under guardianship experiencing consensual, and positive, sexual relationships. Ideally, the right to consent for people able to do so should be preserved when the guardianship is established through a limited guardianship. Where this is not done, inappropriate restriction of rights and ongoing conflict are likely to result. Where the guardian has doubts or concerns about the person's ability to consent, the guardian should explore the availability of counseling for the person in the areas of socialization, personal relationships, and responsibilities in dating and family planning.

There are real risks of sexual abuse, unwanted pregnancy and sexually transmitted diseases. While the "easy solution" to

many of the fears that rise out of friendships that may become sexual may be to totally prevent potential partners from ever being together, or from ever having privacy, this "easy solution" sacrifices the rights of the mentally disabled person to normal friendships and to sexual expression for the peace of mind of others. The best approach will depend on the differing needs and abilities of each individual but should be as close to the normal range of opportunities in our society as possible. A guardian should never assume that the person's need for sexual expression is different or less important than that of other people. It is also important to remember that people have a range of ways of expressing their sexuality; sexual expression does not always have to mean sexual contact.

7. The Right to Due Process of Law

"Due process of law" is a phrase referring to the various rights which a person has when faced with the loss of life, liberty, or property. What those rights actually are depends on the particular situation. Courts have general rules that the more liberty or property that is being threatened to be taken away, the more due process rights the person should have. Among the different due process rights are: 1) the right to be notified that someone is planning to restrict your liberty or take away your property; 2) the right to challenge the intended actions of others; 3) the right to a hearing; 4) the right to be present at all hearings; 5) the right to ask questions of those witnesses who oppose your request; 6) the right to present your own evidence including your own testimony and the testimony of witnesses who support you; 7) the right to have another person assist you in presenting your case; 8) the right to a prompt decision - usually in writing; and 9) the right to appeal the decision. These due process rights of persons are not lessened simply because a person is declared mentally incompetent. Instead, it is the guardian's responsibility to take the steps necessary to see that these rights are enforced on the disabled person's behalf. For example, if a disabled person is being cut off from Medical Assistance or other benefits, that person still has a right to be notified and to challenge the actions of others. It is just that the guardian instead of the ward receives the notice and signs the papers necessary to appeal that decision.

8. The Right to Have Access to Government and the Courts

Even though a person is under guardianship, he or she retains the right to communicate with government officials about his or her treatment and to seek legal advice or court review concerning the need for guardianship, the guardian's actions, or any orders for protective placement or services. For most other types of legal actions, the guardian must begin the lawsuit on the ward's behalf instead of the ward beginning the suit on his or her own.

9. The Right to Vote

Under Wisconsin law, a person who asks to vote may not be denied the right to do so on the grounds of mental incompetence unless the person is under full guardianship of the person or a court has separately found that the person cannot understand the purpose of the elective process. Unless the judge limits a guardianship of the person to allow the person to keep his or her right to vote, the person's vote is lost rather than passed on to the guardian. (The guardian does not get an extra vote.) In general, people should be allowed the dignity of participating in the process if they understand the purpose of voting, or if they can come to understand it with some training.

C. *Other Civil Rights*

1. The Right to Marry

Marriage is different things to different people, but, in addition to love and the capacity to be responsible, the law views marriage as a contract where two people each promise to do certain things in return for the other person also promising to do certain things. The right to marry can be taken away if the judge finds that, because of the person's mental incompetency, the person cannot understand what marriage is about or what he or she is agreeing to do. If the right to

marry is taken away at the guardianship hearing, it is **not** transferred to the guardian. This means that the guardian cannot agree to marriage on behalf of the ward. If the guardian at some point believes that the ward is capable of marriage, the guardian should notify the probate court and ask that this right be restored. If the person wants to marry but lacks the ability to consent, training and counseling may help the person to gain the needed understanding.

2. The Right to Obtain Driver's Licenses and Other Licenses

The guardianship laws specifically allow the court to allow the person the right to obtain licenses. This implies that full guardianship of the person will deprive the person of the right to hold licenses. A court is often not the best place to determine whether a person should or should not hold a state license. Retaining the person's right to obtain a license does not automatically mean that he or she will get one: the person still must meet licensing qualifications of the agency issuing the license. There are probably some people who obviously are not competent to hold a driver's license or certain occupational or professional licenses. For many other people, however, it makes more sense to leave the question to the driver's or other licensing process that is designed to determine individual competence to hold a license. The guardian should take steps to notify the motor vehicle division or other appropriate agency if the ward, who already holds a license at the time of the guardianship hearing, is later found incompetent and the court has not found that he or she may still hold a license.

3. The Right to Testify in Any Judicial or Administrative Proceeding

Being under guardianship does not restrict the person from being a witness, and the person should be allowed to testify if he or she can communicate relevant evidence. It is then up to the judge or jury to decide how far to rely on the person's testimony.

D. *Property Rights*

1. The Right to Hold or Convey Property

If the judge decides that the person is mentally incompetent to hold or convey property, this does not mean the ward cannot own property but rather that the guardian of the estate rather than the ward has the responsibility for managing the property and deciding when to buy or sell property on behalf of the ward. This is done so the person does not let the property go unrepaired or the rents uncollected and so that the person does not buy or sell at unfairly high or low prices. The guardian of the estate manages the property, but title to the property remains in the ward's name and all of the income from the property is for the benefit of the ward. If the guardian decides that the best interests of the ward would be served by selling the property, the guardian must first get court approval of the sale and then use all of the income received from the sale only for the benefit of the ward. The annual report of the guardian of the estate to the court is one of the ways that this is monitored.

2. The Right to Contract

While many of us think of contracts as pieces of paper that are signed when having major remodeling done or a car bought or a loan taken out, contracts that are agreed to orally are much more common. Whenever one person agrees to give up something (usually money but it can also be other belongings, property or time) and another person agrees to provide something (goods, services, property, etc.) in return, that is a contract. Generally, we do not realize how many contracts we agree to until something goes wrong or someone does not do what they are supposed to do. Most of the time the amount of money involved is not enough to make it worth the time and effort to have a written contract, but that does not mean something that two people agree to orally is not a contract. The law allows people to contract with others and recognizes that sometimes one side or the other will be taken advantage of because the other side either has

more information or drives a harder bargain. Although the law generally does not get involved with this unfairness, it does get involved when it finds, in a guardianship hearing, that one person's mental incompetence puts him or her at a constant unfair disadvantage and that he or she should be protected from possible exploitation.

Taking away the person's right to contract has three parts. The first part is that the ward can no longer have the right to insist that the other person or company contract with him or her. This means that although a hotel, store, bank or other company normally is prohibited from discriminating against a person because of a disability, they can refuse to rent a room, sell goods, or give a loan if they know that the person is unable to pay (does not have the money) or does not have the authority to control their funds so that they cannot pay for it. By restricting a person's right to contract, a judge is ordering that a person is not authorized to enter into agreements and, therefore, has no "right" to insist that others contract with him or her.

The second part of taking away the person's right to contract means that even if another person or company does contract with the ward, the contract is presumed to be invalid because the ward does not have the ability to understand what he or she was agreeing to. That means that if a person whose right to contract has been removed signs a contract and the other person or company wants to make the incompetent person keep his or her end of the deal, that other person or company will have to first prove that the person was mentally competent even though a court has previously found that the person was not mentally competent.

The right to contract is not totally removed, but is instead transferred to the guardian to act on behalf of the ward. This means that the ward's money can still be used but the guardian signs contracts on behalf of the ward instead of the ward. For example, imagine a situation where the ward who has had his right to contract restricted, wished to rent an apartment. The landlord may refuse to rent the apartment or to allow the person to sign a lease because he knows the mentally incompetent person has no authority to sign the lease. If the landlord, however, is not aware that the right to contract has been limited by the court, the landlord may decide to rent the apartment and allow the person to sign a lease. If the guardian later finds out that the apartment has been rented or a lease has been signed, the guardian has the responsibility of notifying the landlord as soon as possible of the fact that the ward's right to contract has been limited. If the guardian decides to get the ward out of the rental agreement or lease and notifies the landlord of this, the landlord must give back the unused money and tear up the lease. The guardian may, however, decide that the apartment is okay and the rent is the right amount. In that case, a new contract or lease should be made up with the guardian signing on behalf of the ward. Whenever the guardian signs something on behalf of the ward, the guardian should either sign his or her own name "Gary Guardian, guardian for Wanda Ward," or sign it as "Wanda Ward, by her guardian, Gary Guardian." This will help to make it clear that the guardian is signing something on his or her ward's behalf rather than for the guardian's own personal use. The guardian should also make it clear - in writing - that only the ward's estate will be liable for the contract.

E. General Human Rights - Respect and Dignity

When we use the word "rights" we do not just mean constitutional rights or rights found in laws. We also mean the general human rights which are not found written in books but are, in reality, the respect which we treat each other with each day. When an employer or supervisor unnecessarily yells and humiliates an employee in front of a lot of other people and someone says "he has not right to yell that way" we are not talking about a law that makes it a crime to yell, but rather we are talking about the expectation of being treated with dignity and respect.

It will not come as a surprise to many guardians that people with mental disabilities are frequently denied their human "right" to be treated with respect and dignity. It will most likely be an ongoing task of the guardian to monitor the way the ward is treated by others and to intervene on behalf of the ward when the guardian observes the ward being treated in a dehumanizing way. This does not mean that the guardian is expected to be overprotective or start up a crusade each time the ward experiences one of the disappointments of life which each of us are exposed to. It does mean, however,

that the guardian should attempt to be aware of patterns of behavior by others which indicate the need for some type of informal discussions or informal or formal education to correct that behavior.

F. Rights in Nursing Homes and Residential Facilities

People who live in nursing homes, intermediate care facilities, and community-based residential facilities are protected by a statutory bill of rights. These rights are found in the Wisconsin Statutes at Section 50.09(1). In addition, there are rules that give further detail on these rights in the following chapters of the Wisconsin Administrative Code: HFS 132 (nursing homes); HFS 134 (facilities for the developmentally disabled); and HFS 83 (community-based residential facilities). Copies of the statutes and rules are available in most public libraries. Protected rights include rights to:

1. Have private and unrestricted communications; mail, telephone, and personal visits;
2. Present grievances to operators and public officials;
3. Manage personal finances and/or delegate this responsibility;
4. Be notified of per diem rates, other charges and services;
5. Courtesy, respect and dignified treatment by all staff;
6. Physical and emotional privacy in treatment and living arrangements including privacy in visits and in medical examinations, discussions and records;
7. Not be required to perform non-therapeutic work for the facility;
8. Choice of participation in social, religious and community activities - unless medically contraindicated;
9. Retain and use personal clothing and property (within space limits);
10. Be transferred or discharged, and to be given advanced notice of planned transfer, discharge or alternatives. If discharge is involuntary, it must be based on failure to pay or inability of the facility to meet the person's needs, and it is subject to an appeal process;
11. Be free from mental or physical abuse and unauthorized physical or chemical restraints;
12. Receive adequate and appropriate care within the capacity of the facility;
13. Choose the provider of health care or pharmacist;
14. Be fully informed of and participate in planning treatment and care.

A complete copy of the rights and the facility's grievance procedure should be provided to the person and the guardian at the time of admission. If a person is under full guardianship of the person, the power to protect these rights passes to the guardian. The guardian should read these carefully, since he/she is responsible for exercising and advocating for those rights on behalf of his/her ward.

If a guardian believes the person's rights are being violated, he or she can use the facility's grievance procedure, or he

or she can complain to the Board on Aging and Long Term Care, a state agency which investigates and mediates complaints, or to the regional office of the Bureau of Quality Assurance at the Department of Health and Family Services, which is the agency responsible for enforcing state and federal rules in nursing homes. See Appendix for atrocious and telephone numbers.

G. Bill of Rights for People Receiving Institutional or Community Services for Mental Illness, Developmental Disabilities, Alcoholism or Drug Abuse

When a person receives alcoholism, drug abuse, mental health, or developmental disabilities services in the person's home community or from a private or state facility, whether inpatient or outpatient, he or she has certain rights under Wisconsin Statutes (section 51.61) and Wisconsin Administrative Code (chapter HFS 94). These rights also apply to any person who is protectively placed, including people with infirmities of aging. Covered settings include community services under contract with county community program departments, such as residential service providers and vocational agencies, and to other providers, such as outpatient clinics. One exclusion is that it does not apply to hospital emergency rooms.

Because these rights are specific to treatment for mental disabilities and are available in a wide range of settings, it is important for the guardian to try to become familiar with them. If the person is placed under full guardianship of the person, the guardian has the power and responsibility to exercise the rights on the person's behalf, except where consent of the person is specifically required.

Rights under sec. 51.61 are now enforceable through a grievance procedure which each provider and county is required to adopt. A grievance should first be investigated by the agency you are complaining against, and you have a right to a prompt and written response. Grievances can be appealed for review by the county and then by the state, so that there is a review independent of the agency. You can also bring a lawsuit on the person's behalf to stop violations of rights and to recover actual and exemplary damages for any harm from rights violations. If you are successful, the agency involved may also be required to pay your attorney fees.

Rights protected by sec. 51.61 include the following:

1. Treatment rights. The person has the right...

- To adequate and appropriate treatment, rehabilitation and educational services. This should include the right to learn basic living skills, as well as more formal treatment. This right may now be limited in county-funded

services due to funding considerations. (See Section V-H-4)

- To have the least restrictive treatment condition needed to carry out the purpose of his or her commitment or admission. (See Section V-C) This right also may not be limited in county-funded services due to funding considerations. (See Section V-H-4)
 - To be informed about treatment and care and participate in planning treatment and care.
 - To live in a pleasant physical place, and to have people treat him or her with respect.
-
- To be free of excessive or inappropriate medication and to refuse to take any psychoactive medications or participate in treatment, except under certain circumstances. (See Section V-E-5)
 - To refuse psychosurgery or other drastic treatment. (See Section V-E-5)
 - To refuse to take part in experimental research. (See Section V-E-4)
 - To be free from physical restraint and isolation, except as part of treatment or in an emergency. Restraint and isolation should never be used for convenience of staff or as a substitute for active programming.
 - To have his or her conversations with staff, and all medical and care records kept confidential, and to have access to treatment records. (Confidentiality and access to treatment records are covered by sec. 51.30 of the Statutes.)

2. Personal Rights. The person has the right...

- To choose and wear his or her own clothes and personal articles.
- To have his or her own private storage space.
- To have privacy in dressing, toileting, and bathing.
- To send and receive sealed mail (within certain security precautions).
- To make reasonable use of the telephone.
- To see visitors each day.

[NOTE: The above six rights may be restricted because of the person's treatment or security needs. The person is entitled to notice and an informal hearing, and may complain about restrictions through the grievance procedure.]

- To refuse to be filmed or taped.
- To take part in religious worship.
- To use his or her money as he or she chooses.

3. **Grievances and legal remedies.** The person has the right...

- To present grievances and to communicate with public officials without justifiable fear of reprisal.
- To petition a court for review of any civil commitment order or protective placement.
- To bring an action for damages [§§51.61(7)] against persons violating his or her rights or confidentiality.
- To be considered legally competent unless a judge has found him or her to be incompetent.
- To be told about his or her rights, informed of any legal reasons there may be for denying any of those rights, and be entitled to a hearing before certain rights are taken away.

4. **Other Rights.** The persons has the right...

- To be treated with respect and recognition of dignity by employees and other professionals and service providers.
- To be informed about how much he or she may have to pay for the cost of care and treatment.
- To receive wages for work, except in matters of personal care (e.g., making the bed, keeping his or her area, room and clothes in order), and to refuse to work for the benefit of the facility whether or not he or she is paid.
- To remain silent during any probable cause precommitment interview with a clinical psychologist or psychiatrist (because such interviews are not confidential).

VIII. **COMMUNITY SERVICES FOR PEOPLE WITH MENTAL ILLNESS, DEVELOPMENTAL DISABILITIES OR ALCOHOL OR DRUG ABUSE PROBLEMS**

A. What are Community Services?

Community services are services that help people live, learn and work in their own communities as independently as possible, while at the same time helping the person to develop or retain skills. (See Sections V-C and D) For people with significant mental disabilities, they can often mean the difference between institutionalization and life in a normal home and can provide meaningful, productive activities. For example:

- Augie is an older man who has early stage dementia and a heart condition. He has a visiting nurse who visits three times a week and homemaker services twice weekly. His church provides some meals, transportation assistance,

and visitors to provide social contact and stimulation. The county manages his funds as representative payee. His county case manager is working to get his family more involved.

- John is chronically mentally ill and has a history of being in and out of hospitals. He now lives on his own with the help of a community support program, which provides drop-in assistance to help him with daily living, social and work activities, and money management, and monitors whether he is taking his medication. If he does not show up for one of his meetings, the program actively goes out and finds him to make sure his treatment needs are met.
- Paul is labeled severely mentally retarded, is nonverbal and has a history of challenging behaviors. He needs support in meeting his self-care needs and he needs a lot of supervision. He spent many years in a state Center for the Developmentally Disabled. Now, with funds from the Community Integration Program, he lives in a group home with two other former Center residents. In his new environment, his communication skills are improving, he has become independent in toileting, and he is learning to do many more things for himself.
- Frieda is also labeled severely mentally retarded. She lives at home with her mother. After graduating from school, she had been home with nothing to do and was losing skills she learned in school. Her boredom and frustration was resulting in anger, tantrums and lack of cooperation. Now she works at a hospital supply room, with support from a job coach who helped design a job she could do and provides on-site support and supervision to her and two other workers who have disabilities. She is learning to get to and from work on her own, is learning better communication skills and behaviors that are acceptable in community settings, and has new pride as an adult who works with other adults, nondisabled as well as disabled.

B. Learning How Your Local Community Service System is Organized

Wisconsin relies on counties as the primary organizers of local community services. The sections below describe the various responsibilities of county government, but counties have a lot of freedom to decide how to assign these responsibilities. Most counties now have single Human Service Departments that combine all or most human service responsibilities. To find out where a particular responsibility lies in your county, you can often get help from the county clerk or the office of the director of the county Aging Unit, Human Service, Community Programs or Social Services Department. You can also look in the telephone book under county government for some of the terms mentioned below. Some other terms used in some counties include "Adult Services" or "Long Term Support."

The system is made more complicated because some services are not run through the county. For example, Home Health and Personal Care agencies are often independent of the county and bill directly for Medical Assistance and Medicare funding.

C. Community Services for People with Mental Illness, Developmental Disabilities or Alcohol or other Drug use

Wisconsin's Mental Health Act (Chapter 51) creates a county-based system for planning and delivery of community services for people with mental illness, developmental disabilities or alcohol or other drug abuse problems. The county board of supervisors has the primary responsibility for services to residents of the county, and for emergency services to nonresidents.

The county board is required to establish community services departments to carry out the county's responsibility to plan and deliver services. Most counties have now assigned this responsibility to larger human services departments that provide a wide range of services. Others continue to have separate community program departments, often serving multiple counties. Two counties still have separate boards for developmental disability services. The statutes list a broad range of services the community service boards should provide, including evaluation, treatment, community support, residential and vocational services.

Under the bill of rights that applies to clients of the community service boards (see section VI-K), a person has a right to receive prompt and adequate treatment, rehabilitation and educational services appropriate for his or her condition and a right to the least restrictive conditions necessary to achieve the purposes of the program he or she is placed in. However, the law limits these rights to what counties can do with state and federal funds and legally mandated county matching funds. Unfortunately, state and federal funding is not enough to meet the need for services, and many people are on waiting lists for services or are in institutions because needed community support services are not available, even where community services would be more appropriate and less expensive.

One reason for this is that the state and federal governments provide full funding for institutional care under Medical Assistance, but only provide a set amount for community services. Thus, supportive community services not only require county planning and management, but often require county funds.

Since 1981 the state has vastly expanded funding for the Community Options and Community Integration programs. Through these programs, the state has contained growth of institutions and allowed many people to choose to remain in their own homes and communities with individualized support services. (See Section VIII-E)

It is important that the lack of adequate services for a ward should not simply be accepted by a guardian. The first step should be to discuss the issue informally with agency or county staff. If this does not work, the guardian can make a written grievance under the agency's or board's grievance procedure under § 51.61 of the statutes and HFS 94 of the Wisconsin Administrative Code. (See Section VII-G), noting the rights that the guardian thinks have been violated. State law and rules now provide for an appeal to the county and state levels under the grievance procedure, so that an independent review is available. Unfortunately, the law may allow funding to be used as a defense where the only rights violated are those to least restrictive or appropriate services.

In cases where there is a significant violation of a person's rights and the grievance process does not work, a guardian may consider taking legal action under § 51.61, the statute which authorized lawsuits to enforce rights, including a right to attorney fees if the person is successful.

A final method of advocacy is to try to change the service system itself. One of the rights of people in our society is to petition the government for change. While it is not a legal duty of the guardian, it is certainly appropriate for a guardian to act as a spokesperson for the person on public issues. One approach is to ensure that the county agency does not simply ignore unmet need: while a community services department cannot spend money it does not have, it is responsible for identifying unmet needs and developing plans to meet those needs. A good plan can help to ensure that resources are used fairly, and that unmet needs are not ignored. Ultimate funding responsibility lies with the county board and state legislature, and the guardian may wish to contact the person's county supervisor and state legislators concerning gaps in the service system.

D. Social Service Departments

The county Department of Social Services provides a broad range of services which are not necessarily limited to people with mental disabilities but which may be helpful in arranging a package of support services. Social service agencies often have primary responsibility for services for people who are elderly or physically disabled, including funding for an attendant or home worker to provide personal care, meal preparation, housekeeping and chore services in the person's home. In many counties the social service agency is the lead agency for the protective service system and the Community Options Program. Social service departments also operate benefit programs including Medical Assistance and Food Stamps.

If social services or other benefits are denied or cut back, the person usually has a right to a hearing to challenge the agency's action. Notice of how to request a hearing should be given with the notice of the agency's action.

E. County/Tribal Aging Units

Every county and tribe in Wisconsin has a designated "aging unit" responsible for planning and carrying out certain programs for older people, including nutrition programs, transportation, information and referral, benefit specialist services, etc. These units may also manage other long-term care services and elder abuse services, but in any case they can tell you where to find those services in your county.

F. Lead Elder Abuse Agency

The **elder abuse** law requires the county to designate a lead agency to establish an elder abuse reporting system in the county. That agency then coordinates other agencies that are participating in the elder abuse reporting system, identifies agency responsibility for investigation of reports of abuse, neglect, self-neglect and material abuse and arranges for provision of services.

The **elder abuse reporting system agency** has the following functions, in addition to its planning and coordination functions:

- Receiving and either investigating or referring reports of abuse, neglect, self-neglect or material abuse.
- Publicizing the existence of the reporting system.

- Notifying law enforcement officials in appropriate cases.
- Offering and providing needed services, within available funding.

G. Protective Services Agency

Ch. 55 requires each county board of supervisors to designate one or more county departments to act as the *protective services agency*, with responsibility for local planning to implement the protective service system. The county may designate one or more of the following departments: Human Services, Social Services, Community Programs (51.42) and Developmental Disabilities Services (51.437).

Some counties have created agencies with "protective service" in the title. However, the statute is not about creating an agency or unit. It is about distributing protective service responsibilities at the county level so that people in the system know who is supposed to do what before the inevitable report of abuse, neglect and exploitation comes in, and so there is some plan in place to identify and prevent abuse, neglect and exploitation. A county may decide, for example, that abuse and neglect complaints for elders will be handled by the aging unit while those for people with developmental disabilities will be handled by the community programs unit.

The PSA has responsibility for local planning for the protective service system. In addition, it has been given many specific powers and responsibilities, including:

- Receiving and investigating reports that individuals placed by their guardians in certain settings object to those placements, and ensuring that such placements meet legal requirements. (See Sections V-F and V-H-2)
- Provision of protective services. (See Section V-H-1)
- Petitioning the courts for guardianship, protective placement and protective services.
- Cooperating with the court in securing resources for comprehensive evaluations in protective placement cases.
- Acting as the agency through which protective placements are made, with primary responsibility for implementing and funding appropriate placements.
- Completion of annual reviews of protective placements.
- Development of requirements for annual reports of guardians of the person.
- Making of emergency protective placements.

H. Community Options Program and Community Integration Program

The original Community Options Program (COP) is an effort to provide funding for community services to people who would otherwise qualify for care in a nursing home or facility for people with developmental disabilities. COP provides funds to individually assess people to determine if services can be provided in the community and develop an individual plan for services. If services can be delivered that will meet the person's needs with funds available, COP uses highly flexible state funds to fund those services. Unfortunately, COP funds are limited and not all eligible people can be served.

After the original COP program began, the federal government changed its rules to allow states to get waivers to spend federal Medical Assistance funds to provide community services for people who otherwise would be eligible for certain types of institutional care. Available services include case management, residential support services, day services, work-related services, counseling, daily living skills training, home modification, adaptive equipment, home health, personal care, habilitation, respite, day treatment, and psychosocial services.

The state sets average daily rates for the MA waiver programs. Because these are averages, particular individual plans may provide for funding above or below the average. The state averages are below what the federal government would allow, so if a county does exceed the overall average it can generally use the money it spends to obtain federal reimbursement for 60% of its excess costs. MA waiver services can be combined with COP funding, SSI and MA card services. For a person to participate, the program requires agreement from the county responsible for providing the services and consent from the person or the person's guardian, if any, unless a court orders community placement. Wis. Stat. §§ 46.275(4)(b)1., 2.; 46.277(4)(a); 46.278(5).

Wisconsin is currently operating several waiver programs:

- *Community Integration Program for Residents of State Centers (CIP-1a)*

CIP-1a, § 46.275, provides funding for home and community-based services to people placed out of one of the three state centers for the developmentally disabled. The state has increased the CIP-1a rate in recent years in an effort to encourage community placements of residents of the state centers. The average daily rates as of July, 1997, were \$153 for new placements and \$125 for continuing placements made before July, 1995. These amounts are designed to cover actual county placement costs, but counties that spend more can be reimbursed for 60% of their excess costs.

- *Community Integration Program for Person with Mental Retardation (CIP-1b)*

CIP-1b, § 46.278, provides funds (an average of \$48.33 per day in 1997) for community placement and services to people with developmental disabilities who are living in nursing homes or intermediate care facilities for the mentally retarded (ICF-MRs) other than the state centers, or who are in the community but would qualify for a level of care provided in an ICF-MR. Funding from the state to provide the state match for CIP-1b is limited, and is most likely to be available for individuals relocated from institutional setting. Counties can almost always obtain the federal matching portion (60%) of CIP-1a if they are willing and able to come up with the 40% state match, from COP Community Aids, or county tax levy funding. State funding and a higher daily rate are available individuals are relocated from a facility that is closing. Section 46.278(6)(e).

- *Community Supported Living Arrangements Waiver*

This waiver is very similar to CIP-1b, but is intended to provide more flexibility and consumer control in the methods of support. The county must provide the state match from COP, Community Aids, or local funds.

- *Brain Injury Waiver*

Services under the Brain Injury Waiver are available to persons with brain injury, as defined in § 51.01(2g), who need service similar to those provided in institutional rehabilitation programs for people with brain injury. The average daily rate is \$170 per day.

- *Community Integration Program for Persons Relocated From or Eligible for Nursing Home Care (CIP-II)*

CIP-II, section 46.277, provides funding to counties for community services for people who are relocated from nursing homes or who need a level of care that MA would pay for in a nursing home. It is available only in counties in which a nursing home has closed or been reduced in size. For example, a county with a 200-bed nursing home might choose to rebuild a 100-bed home and receive CIP-II funding for 100 service “slots” to serve people in community settings. CIP-II is generally not available to serve people who are not elderly and who need services primarily because of chronic mental illness or mental retardation. The average daily rate is \$40.78, and state matching funds are provided up to that rate.

- *Community Options Program-Medical Assistance Waiver (COP-W)*

The COP-W waiver, section 46.27(11), is intended to provide federal funds to supplement the reimbursement usually available under COP for elderly or physically disabled people who need a level of care that MA would pay for in a nursing home. The average daily rate is \$40.78, but local county match may be required.

I. Community Support Services for People with Mental Illness

Community support is a key service for preventing institutionalization of people with persistent mental illness. Section 51.421 requires that each DCP establish a community support program for people with chronic mental illness. Standards for these programs are contained in HFS 63, Wis. Admin. Code. Community support services can now be funded as a Medical Assistance service, making it more affordable for counties. However, unlike most other MA card services, counties must provide the state portion of funding. As a result, local service availability is dependent on county funding commitments.

J. Home Health and Personal Care Services

Home health (including nursing, home health aide, therapy and medical equipment), private duty nursing and personal care together have recently been the fastest-growing service under the Medical Assistance program. MA does not require that the person be “home-bound” to receive most these services, except for in-home therapy services. These services are now an important part of the long-term support service package for many people, particularly those on waiting lists for other long-term support programs.

Home health and personal care services are arranged through certified providers. For many services, the provider must get prior authorization from the state Bureau of Health Care Financing. Denials of eligibility and denials or reductions of service coverage can be appealed through an administrative fair hearing process.

Medicare also covers nursing and home health aide services, but does not cover personal care. Medicare requires that the person need a skilled nursing or therapy service to be eligible for coverage.

K. Supplemental Security Income Exceptional Expense Supplement

Supplemental Security Income (SSI) provides income maintenance payments to people who are over age 65, blind, or disabled, and who meet income and resource standards. It is an important source of funds for basic living expenses in community settings, particularly because MA waiver rules limit use of MA funds for room and board expenses. People on SSI generally receive both a federal SSI payment and a state “supplement.” The federal payment is administered by the Social Security Administration, while the state supplement is now administered separately by the state Department of Health and Family Services. A special increased state supplement level called SSI-E is available for people who need

40 or more hours per month of supportive home care, daily living skills training or community support services. The person must be certified by the county to get this increased payment level.

IX. LEGAL ASSISTANCE

One of the guardian's roles is to advocate for the person in legal proceedings. If the guardian feels strongly that the person's rights or interests have been damaged and that less formal advocacy is not effective, he or she may want to begin a lawsuit to assert those rights or interests.

In choosing an attorney, the guardian or person should not be afraid to call several attorneys to ask about fees and experience in working on issues involving people with disabilities. If you do not know of any lawyers, it may be useful to ask people in similar situations if they can recommend someone. The state bar also runs a referral and information service that can give you the names of lawyers who work on cases like yours. Their number is toll-free: 1-800-363-9082.

When a guardian of a person is appearing on behalf of the ward, the costs of litigation should be expected to be paid out of the ward's estate. Therefore, it is important for the guardian of the person to discuss this with the guardian of the estate and to get the financial support of the estate guardian. If the ward has low income he/she may be eligible for free legal services. If no government legal services program is available, a guardian might be able to locate an attorney who is willing to donate his/her services or, if there is a possibility of recovering damages (money from the people being sued), would be willing to take the case on a contingent fee basis.

Sometimes disputes might arise between the guardian and the ward. In most instances, they will be able to work out an agreement, but it is possible that the dispute will finally have to be resolved by the court. For example, the ward may wish to get married but the guardian strongly opposes such a marriage. The ward could try to go back to court to get a modification of the findings of incompetency which would return the right to get married. Depending upon the strength of the guardian's opposition and/or degree of incompetency, the guardian could choose to simply appear at the court hearing and ask to testify to the judge as to the reasons why marriage would not be in the ward's best interest. But if the guardian's feelings were extremely strong or the facts of the case were very marginal, the guardian might want to hire an attorney to represent the guardian's position. If the guardian's position prevails, the court may determine that the guardian's court expense shall be paid by the ward's estate if the court first determines that the guardian was fulfilling her/his statutory responsibilities in taking the position. However, since neither victory nor an awarding of attorney fees can generally be assumed, guardians should not count on the ward's estate to pay the guardian costs.

Possible sources of legal advice and assistance are listed in the Appendix.

X. LEARNING MORE

The Appendix contains a resource list of agency names and addresses which can be sources of more information on legal issues, specific disabilities, evaluation resources, long-term support services, and government programs.

The following two books provide greater detail and legal citations on many of the issues discussed in this handbook:

Chapter 51: The Wisconsin Mental Health Law (1993; publication ID # PCS 461).

Chapter 55: The Wisconsin Protective Services Law and Its Application (1994, publication order ID # PCS-460a).

For copies of these publications, contact:

Department of Health and Family Services
Division of Supportive Living
ATTN: Publications Order
One West Wilson St.
P.O. Box 7851
Madison, WI 53707-7851

Requests should be made by either completing a DMS-25 FORMS/PUBLICATIONS ORDER or by sending a written request which includes the publication identification number, the number of copies, your name, a complete return address (including street address) and a phone number where you can be reached in case questions arise.

Other useful reading material includes:

Doubly Silenced: Sexuality, Sexual Abuse and People with Developmental Disabilities. Madison, WI: Wisconsin Council on Developmental Disabilities (1991).

Durable Powers of Attorney for Finances and Other Property. Madison, WI: Elder Law Center.

Elder Abuse: Potential Legal Remedies. Madison, WI: Wisconsin Coalition Against Domestic Violence.

Finding a Way Toward Everyday Lives: The Contribution of Person Centered Planning. Harrisburg, PA: Pennsylvania Office of Mental Retardation (1992). (Copies available from the state Bureau of Developmental Disabilities Services.)

One Step Ahead: Resource Planning for People with Disabilities Who Rely on Supplemental Security Income and Medical Assistance. Madison, WI: Wisconsin Council on Developmental Disabilities (1997).

No Easy Answers: Seeking consensus when considering psychotropic medication for individuals with developmental disabilities. Madison WI: Wisconsin Council on Developmental Disabilities (1996).

Overview of Medical Assistance Lien Law and Estate Recovery Program. Madison, WI: Elder Law Center (1996).

Planning for Future Health Care Decision-Making: DO-IT-YOURSELF PACKET. Madison, WI: Elder Law Center

A guardian may also want to have direct access to relevant laws and rules. These are often available in the reference section of public libraries. Laws and rules that are often important for guardians to be aware of include:

Wisconsin Statutes

- Ch. 46 Social Services (including programs on aging)
- Ch. 49 Public Assistance (including Medical Assistance)
- Ch. 50 Uniform Licensure (including nursing homes, community-based residential facilities, and adult family homes)
- Ch. 51 Alcohol, Drug Abuse, Developmental Disabilities and Mental Health
- Ch. 55 Protective Services
- Ch. 880 Guardianship

Wisconsin Administrative Code

- Ch. HFS 1 Uniform Fee Schedule
- Ch. HFS 61 Community Mental Health Services
- Ch. HFS 63 Community Support Programs for Chronically Mentally Ill Persons
- Ch. HFS 83 Community-Based Residential Facilities
- Ch. HFS 85 Non-Profit Corporation as Guardian
- Ch. HFS 88 Licensed Adult Family Homes
- Ch. HFS 89 Assisted Living Facilities
- Ch. HFS 92 Confidentiality of Treatment Records
- Ch. HFS 94 Patient Rights and Resolution of Patient Grievances
- Ch. HFS 100 Medical Assistance
- Ch. HFS 118 Confidential Information
- Ch. HFS 125 Do-Not-Resuscitate Orders Directed at Emergency Health Care Personnel
- Ch. HFS 131 Hospices
- Ch. HFS 132 Nursing Homes
- Ch. HFS 133 Home Health Agencies
- Ch. HFS 134 Facilities for the Developmentally Disabled

APPENDIX: RESOURCE LIST

Legal Advocacy Resources

WISCONSIN COALITION FOR ADVOCACY

16 N. Carroll Street, Suite 400
Madison, WI 53703
(608) 267-0214
(800) 928-8778

2040 W. Wisconsin Ave., Ste. 678
Milwaukee, WI 53233
(414) 342-8700

The Wisconsin Coalition for Advocacy is an independent, private nonprofit corporation that has been designated as the protection and advocacy agency for people with disabilities in Wisconsin under the federal Developmental Disabilities Services and Bill of Rights Act, the Protection and Advocacy for Mentally Ill Individuals Act and the Rehabilitation Act. WCA uses a broad range of strategies, including advocacy for individuals, assisting with local and state systems change efforts, and training and program evaluation. WCA staff offer advice and advocacy statewide to people with developmental disabilities, people with mental illness in residential settings, people with other substantial disabilities, and people in need of assistive technology. Case acceptance may depend on case priority and resource limitations.

ELDER LAW CENTER OF THE COALITION OF WISCONSIN AGING GROUPS

2850 Dairy Drive, Suite 100
Madison, WI 53718
Madison 608-224-0660 / 1-800-488-2596

The Elder Law Center operates the **Wisconsin Guardianship Support Center** which provides toll-free telephone hotline case consultation services on guardianship and advance directives issues, a quarterly newsletter, trainings and technical assistance to counties. The Elder Law Center also provides legal back-up to county-based benefit specialists providing information and assistance on public benefits and health care financing issues for people over 60.

LEGAL AID SOCIETY OF MILWAUKEE

229 E. Wisconsin Ave., Suite 200
Milwaukee, WI 53202
(414) 765-0600

The Society provides legal assistance to low income persons. A major part of its work is representation of Milwaukee County residents with mental and other disabilities.

OFFICE OF THE STATE PUBLIC DEFENDER

If a person is accused in a criminal case or is the subject of a civil commitment, protective placement or termination of parental rights action and cannot afford a lawyer, the person may be entitled to a public defender or a lawyer appointed by the court. Contact the local Public Defender office or the court for information.

The following four programs provide free legal assistance for people with low incomes within case priority and resource limitations:

LEGAL ACTION OF WISCONSIN

Madison - 608-256-3304 or 800-362-3904 (Columbia, Dane, Dodge, Green, Jefferson and Rock Counties)
31 S. Mills Street, P.O. Box 259686 Madison, WI 53725-9686

Milwaukee - 414-278-7722 or 888-278-0633 (Milwaukee and Waukesha Counties)
230 W. Wells Street, Milwaukee WI 53203

Kenosha/Racine - 414-654-0114 or 800-242-5840 (Kenosha, Racine and Walworth Counties)
508 56th Street, Kenosha, WI 53140

LaCrosse - 608-785-2809 or 800-873-0927 (Buffalo, Juneau, La Crosse, Monroe, Trempealeau, Jackson and Vernon Counties)
205 5th Avenue South, #300, LaCrosse, WI 54601

Dodgeville - 608-935-2741 or 800-873-0928 (Crawford, Grant, Iowa, Lafayette, Richland and Sauk Counties)
202 N. Main Street, Dodgeville, WI 53533

LEGAL SERVICES OF NORTHEASTERN WISCONSIN

Green Bay - 920-432-4645 or 800-236-1127 (Brown, Calumet, Green Bay, Door, Kewaunee, Manitowoc and Outagamie Counties)
201 W. Walnut St., Suite 203, Green Bay, WI 54303

Oshkosh - 920-233-6521 or 800-236-1128 (Adams, Green Lake, Oshkosh, Fond du Lac, Marquette, Ozaukee, Sheboygan, Washington, Waushara and Winnebago Counties)
404 N. Main St., Ste. 702, Oshkosh, WI 54901

WISCONSIN JUDICARE

Wausau - 715-842-1681 or 800-472-1638 (All other counties)
300 3rd Street, Ste. 210, Wausau, WI 54402

Statewide Disability and Aging Organizations and Councils

Alliance for the Mentally Ill of Wisconsin
4233 West Beltline Highway
Madison, WI 53711
(608) 268-6000 / 800-236-2988

The Arc – Wisconsin
121 South Hancock Street
Madison, WI 53703
(608) 251-9272
(Advocating for people with mental retardation and their families)

Autism Society of Wisconsin
103 West College Ave., Ste. 709
Appleton, WI 54911
(920) 993-0279 / 888-428-8476

Badger Association of the Blind
912 North Hawley Road
Milwaukee, WI 53213
(414) 256-8744 / 877-258-9200

Coalition of Wisconsin Aging Groups
2850 Dairy Drive, Ste. 100
Madison, WI 53718
(608) 224-0606 / 800-366-2990
(Including the Elder Law Center and Guardianship Support Center)

Easter Seal Society of Wisconsin
101 Nob Hill Rd., Ste. 301
Madison, WI 53713
(608) 277-8288 / 800-422-2324

Rehabilitation for Wisconsin
4785 Hayes Road, Ste. 202
Madison, WI 53704
(608) 244-5310

Waisman Center on Mental Retardation and Human Development
University of Wisconsin – Madison
1500 Highland Avenue
Madison, WI 53705-2280
(608) 263-5776
(Clinical services, evaluation, research and training on mental retardation, communication, mobility, etc.)

Wisconsin Association on Alcohol and Other Drug Abuse
6441 Enterprise Lane, Ste. 105

Madison, WI 53719-1180
(608) 276-3400

Wisconsin Association of Residential Facilities
1123 North Water Street
Milwaukee, WI 53202
(414) 276-9273

Brain Injury Association of Wisconsin
2900 North 117 Street, Suite 100
Wauwatosa, WI 53222
(414) 778-4144 / 800-882-9282

Wisconsin Council of the Blind, Inc.
754 Williamson Street
Madison, WI 53703
(608) 255-1166 / 800-783-5213

Epilepsy Association of Wisconsin
6400 Gisholt Drive
Madison, WI 53713
800-733-1244

Independent Living Centers and Alzheimer's Association Chapters

Independent Living Centers

Wisconsin Coalition of Independent Living Centers
2345 Atwood Avenue
Madison, WI 53704
(608) 242-8484 / 800-362-9877

Independence First
600 West Virginia Street, 4th Floor
Milwaukee, WI 53204-1516
(414) 291-7520

Society's Assets
5200 Washington Avenue, #225
Racine, WI 53406-4238
(414) 637-9128

North Country Independent Living
2231 Catlin Avenue
Superior, WI 54880
(715) 392-9118

CILWW – UW Stout
2920 Schneider Avenue East
Menomonie, WI 54751
(715) 233-1070 / 800-228-3287

Great Rivers ILC
4328 Mormon Coulee Road
La Crosse, WI 54601-4018
(608) 787-1111

Options for Independent Living Program
555 Country Club Road
Green Bay, WI 54307
(920) 490-0500

Access to Independence
2345 Atwood Avenue
Madison, WI 53704

WI Alzheimer's Association

Greater Wisconsin Chapter
2900 Curry Lane, Suite A
Green Bay, WI 54311
(920) 469-2110 / 800-360-2110

Ashland Region
201 W. Main, Room 105A
Ashland, WI 54806
(715) 682-6478 / 800-682-6478

Green Bay Region
2900 Curry Lane, Suite A
Green Bay, WI 54311
(920) 469-2110 / 800-360-2110

Eau Claire Region
1227 B Menomonie St.
Eau Claire, WI 54703
(715) 835-7050 / 800-499-7050

La Crosse Region
115 5th Avenue South, #421
La Crosse, WI 54601
(608) 784-5011 / 800-797-1656

Fox Valley Region
201 East Bell Street
Neenah, WI 54956
(920) 727-5555, ext.209 / 800-360-2110

Rhineland Region
203 Schiek Plaza
Rhineland, WI 54501
(715) 362-7779 / 800-200-1221

Wausau Region
1000 Lakeview Drive, P.O. Box 1469
Wausau, WI 54402

(608) 242-8484

Midstate Independent Living
203 Schiek Plaza
Rhinelander, WI 54501
(715) 369-5040

(715) 848-1221 / 888-297-6605

South Central Wisconsin Chapter
517 North Segoe Road, Suite 301
Madison, WI 53705
(608) 232-3400

State Government Disability and Aging Offices

Bureau of Aging and Long
Term Care Resources
1 West Wilson St., Room 450
Madison, WI 53702
(608) 266-2536 – General Number
(608) 267-7285 – Long Term Support
(608) 267-9582 – Physical Disabilities
(State coordination of Older Americans Act
programs as well as the Community Option
Program, Community Integration Program-II,
housing, and other long-term support issues.
Also responsible for Elder Abuse and Adult
Protective Services.)

Bureau of Developmental
Disabilities Services
1 W. Wilson Street, Rm. 418
Madison, WI 53702
(608) 266-0805
(Community services and Community Inte-
gration Program for people with developmental
disabilities)

Bureau of Health Care Financing
P.O. Box 309
Madison, WI 53701-0309
(608) 266-2522
(Medical Assistance coverage and payment
issues)

Bureau for Deaf & Hard of Hearing
1 W. Wilson St., Room B275
Madison, WI 53702
(608) 266-3118

Bureau for the Blind
1 W. Wilson St., Room B275
Madison, WI 53702
(608) 267-2903

2811 Agricultural Drive
Madison, WI 53708-8911
(608) 224-5070
800-362-1290
(Handles questions and complaints concerning
Division of Vocational Rehabilitation services)

Council on Alcohol and Other Drug Abuse
Bureau of Substance Abuse Services
1 West Wilson Street, Rm. 434
Madison, WI 53702
(608) 266-2717

Council on Developmental Disabilities
Council on Physical Disabilities
Division of Supportive Living
722 Williamson Street
Madison, WI 53703
(608) 266-7826

Council on Independent Living
Division of Supportive Living
1 W. Wilson St., Rm. B275
Madison, WI 53702
(608) 266-3274

Council on Mental Health
c/o Bureau of Community Mental Health
1 West Wilson Street, Rm. 433
Madison, WI 53702
(608) 267-7792

Division of Care and Treatment Facilities
1 W. Wilson, Rm. 850
Madison, WI 53702
(608) 266-8740
(Administers state mental health institutes and
centers for the developmentally disabled)

Client Assistance Program

Division of Equal Rights
Department of Workforce Development
201 East Washington Avenue
Madison, WI 53702
(608) 266-6860
(Discrimination in employment, housing, or
public accommodations)

Division for Learning Support: Equity and
Advocacy
Exceptional Education
Department of Public Instruction
125 S. Webster
Madison, WI 53703
(608) 266-1781

Division of Vocational Rehabilitation
Department of Workforce Development
201 East Washington Ave, Room A100
Madison, WI 53702
(608) 261-0050

Long Term Support & Physical Disabilities
Bureau of Aging and Long Term Care
Resources
1 W. Wilson Street, Rm. 450
Madison, WI 53702
(608) 267-7285 - Long Term Support
(608) 267-9582 - Physical Disabilities

Bureau of Quality Assurance
1 W. Wilson Street, Rm. 1150
Madison, WI 53702
(608) 266-8481
(Enforcement of rights and regulations in nursing
homes, state centers, residential facilities and
home health services)

Regional Offices:

Regional Field Operations Director
Southern Region
2917 International Lane, Suite 210
Madison, WI 53704-3135
(608) 243-2370
(608) 243-2389 – Fax
Regional Field Operations Director

Southeastern Region
819 North 6th Street, Rm. 210
Milwaukee, WI 53203
(414) 227-5000
(414) 227-3903 - Fax

Regional Field Operations Director
Northeastern Region
200 North Jefferson Street, Suite 211
Green Bay, WI 54301
(920) 448-5240
(920) 448-5254 - Fax

Regional Field Operations Director
Western Region
610 Gibson Street, Suite 1
Eau Claire, WI 54701-3687
(715) 836-4752
(715) 836-2535 - Fax

Regional Field Operations Director
Northern Region
1853 North Stevens, Suite B
Rhineland, WI 54501-1246
(715) 365-2800
(715) 365-2815 - Fax

